

**Exploring socio-cultural factors influencing  
adherence to the treatment of type 2 diabetes  
in rural Sargodha**



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**Quaid-i-Azam University  
Department of Anthropology  
Islamabad - Pakistan  
2020**

# **Exploring socio-cultural factors influencing adherence to the treatment of type 2 diabetes in rural Sargodha**



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Thesis submitted to the Department of Anthropology, Quaid-i-Azam University Islamabad, in partial fulfillment of the degree of Philosophical Doctor in Anthropology.

Quaid-i-Azam University  
Department of Anthropology  
Islamabad - Pakistan  
2020

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Islamabad, 27 August 2020



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# Exploring socio-cultural factors influencing adherence to the treatment of type 2 diabetes in rural Sargodha



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(Department of Anthropology)

Dated: 26<sup>th</sup> August, 2020

**Certificate of Approval**

This is to certify that the research work presented in this thesis, entitled “**Exploring Socio-cultural factors influencing adherence to the treatment of type 2 diabetes in rural Sargodha**” was conducted by **Mr. Shaheer Elahi Khan**, under the supervision of Dr. Anwaar Mohyuddin, Assistant Professor Department of Anthropology, Quaid-i-Azam University, Islamabad.

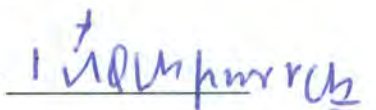
No part of this thesis has been submitted anywhere else for any other degree. This thesis is submitted to the Department of Anthropology, Quaid-i-Azam University, Islamabad, in the partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Field of **Anthropology**, Department of Anthropology, Quaid-i-Azam University, and Islamabad.

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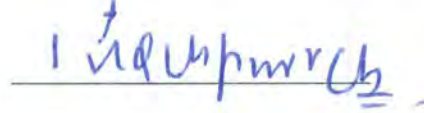
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**Shaheer Ellahi Khan**



## Abstract

A pragmatic cluster randomized controlled trial- a pilot intervention was conducted to assess the effectiveness of a standardized care package of diabetes-cardiovascular disease delivered through rural primary healthcare facilities in District Sargodha, Punjab, Pakistan. Diabetes patients were recruited into intervention and control arms. The diabetes care package required a skill mix beyond medical knowledge i.e. the counseling tool for life style modification and drug regimen and follow-up adherence that needed to be refined and understood in many dimensions including socio-culturally. Any effort to improve case management required more in-depth understanding of lay belief systems, cultural norms, access to information and products, social service context etc. The adherence to the proposed treatment was indeed an important dimension to explore that explained the socio-cultural barriers (that may further be considered and incorporated in the general framework of the diabetes care package). The current study was designed as one of its own kind research to further contextualize the diabetes care package, by making an intervention site an entry point in the lives of the diabetics. The patients registered at the Rural Health Center 104 Northbound health facility were studied in their local settings.

The study adapted the patients' explanatory model to explore the journey/episode of type 2 diabetes. The study also particularly explored the experience and socio-cultural factors that shapes the general perception towards type 2 diabetes and its adherence to the proposed treatment (i.e., medication and lifestyle change). The study used an interview guide along with observational checklist to conduct in-depth interviews with adherent (male and female) and non-adherent patients (male and female).

The adherence to the proposed treatment was found to be influenced by both direct and in-direct factors. The treatment was found to be two pronged (i.e. clinical treatment and lifestyle modification). The direct social factors towards adherence to the clinical treatment were the perception(s) towards public health care system, role of paramedic, opportunity cost and social identity of diabetic. The in-direct factors were also found to

be cross cutting with the direct social factors. The in-direct factors were the overall environmental factors, education, health illiteracy and age. The adherence to the lifestyle modification was also found to be influenced by certain cultural factors (both directly and in-directly). The direct cultural factors that may affect adherence to the lifestyle change were the concept of diet, concept of physical activity, gender and perception towards the treatment of diabetes (especially desire for cure and maximum benefits). The in-direct cultural factors were also found to be cross cutting with direct cultural factors that may include perceived seriousness of diabetes, financial pressures, position status in the family and environmental factors. The overall adherence to the proposed treatment was majorly influenced by the gender (of the patient).

It may be concluded that adherence to the treatment (clinical treatment and lifestyle modification) was a strong socio-cultural construct. The adherence to the treatment may be improved with the help of understanding the patients' perspective that may lead to develop culturally competent strategies to troubleshoot barriers at the important stages of the diabetes care. It may also be concluded that the range of health care providers may be considered as important stakeholders in the different stages of the disease. The incorporation of these health care providers in the general framework may help educate and refer the patients in case of emergency and complications to the RHC.

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# **1. INTRODUCTION**

The effective treatment of the non-communicable diseases is a cornerstone of prevention and efficient management, and may also add in addressing and troubleshooting the challenges to the primary level public health care establishments in the context Punjab, Pakistan. Since poor treatment adherence is a complex problem with many contributing factors, there is no one universal solution. Adherence to treatment is defined as the extent to which a person's behavior in taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider. Patients presenting with type 2 diabetes mellitus are initially encouraged to maintain a healthy diet and exercise regimen, followed by early medication that generally includes one or more oral hypoglycemic agents and later may include an injectable treatment. To prevent the complications associated with type 2 diabetes, therapy frequently also includes medications for control of blood pressure, dyslipidemia and other disorders.

In order to have an in-depth understanding of the context that may help implement and advance scalability of any intervention regarding the treatment of type 2 diabetes, socio-cultural factors need to be explored and also find how these factors influence and affect the overall episode of type 2 diabetes. The local context takes the issue beyond the health facility and may provide lens to further understand the factors that influence/affect the adherence to the proposed treatment.

## **1.1 Non communicable diseases**

Non-communicable diseases (NCDs) are also known as chronic diseases. A non-communicable disease is a medical condition which is by definition non-infectious and non-transmissible between people (Beaglehole , et al., 2011) (Oh, 2013). These diseases have a long duration and are caused by combination of genetic, physiological, behavioral and environmental factors. Although there is a wide variation in the concept of what can be included in NCDs, the term is theoretically reserved for a group of preventable diseases that are linked by common risk factors ( Pakistan: tripartite collaboration of the Ministry of Health, Government of Pakistan; WHO, Pakistan office, and Heartfile, 2004).

The main types of NCDs are cardiovascular diseases (like heart attacks and stroke), diabetes, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and cancers.

Non communicable diseases are responsible for almost 40 million people deaths each year which make around 70% of all the deaths globally. Every year the number of premature deaths of people between the ages of 30 and 69 years are estimated to be 15 million (World Health Organization, 2017). Out of these premature deaths 80% happen in low and middle income countries. In the year 2015, 3 out of 4 deaths due to NCDs, happened in low and middle income countries and 48% of deaths were of those aged less than 70 years. (World Health Organization, 2017) Throughout the world both men and women are almost equally affected by NCDs. (World Health Organization, 2017) The contribution to annual deaths of the four major types of non-communicable diseases is 17.7 million from cardiovascular diseases, 8.8 million from cancer, 3.9 million from respiratory diseases and 1.6 million from diabetes. (World Health Organization, 2017)

In all societies and economies, non-communicable diseases are known to have adverse human, social and economic consequences. However they are devastating for poor and vulnerable populations. All other causes put together lead to less deaths as compared to the deaths caused by non-communicable diseases alone. (WHO, 2014) (WHO, 2014)

In the last decade there has been a shift from communicable to non-communicable diseases in Pakistan also. (Jafar, et al., 2013) Almost half of the population of Pakistan, which is estimated to be almost 195 million (worldometers, 2016), suffers from a chronic non communicable disease (Wasay M. Z., 2014). Non communicable diseases and injuries are known to be among the top ten causes of both morbidity and mortality combined (Hyder & Morrow, 2000) and almost twenty five percent of overall deaths alone in Pakistan (Federal Bureau of Statistics, Statistics Division, 2003). An estimated 2000 people die each day due to a preventable non-communicable disease (Jafar, et al., 2013). The data of Global Burden of Disease 2010 suggests that in Pakistan, non-communicable diseases and injuries account for 77% of age standardized deaths (Lozano, et al., 2012). Non communicable diseases are known to have the most adverse effects on

adults and mostly the economically productive workforce which are most likely to have these diseases. Hence individuals, societies and the health systems are immensely burdened by NCDs (World Health Organization, 2000) (World Health Organization, 2002) (World Health Organization, 2001). In Pakistan, an estimated 40 million individuals have high blood pressure, 32 million have heart disease, 24 million have obesity, 18 million have high cholesterol, 8 million have diabetes and about 50 million have mental health disorders. (Wasay, Khan, Zaidi, & Jooma, 2014)

Following the current rate the burden of non-communicable diseases is expected to rise by 10-15 percent in the following ten years. Projections made from population level mortality rates also suggest that due to NCDs like cardiovascular diseases, cancers and chronic respiratory diseases, an approximated 3.87 million of Pakistanis will lose their lives between 2010 and 2025. (Jafar, et al., 2013) NCDs lead to significant morbidity and mortality rates as well as impose a substantial economic burden on the individuals, societies and health systems. (World Health Organization, 2000) The burden of these diseases is mostly borne by the economically productive workforce. In Pakistan, the probability of dying between the age of 30 and 70 due to one of the four main non-communicable diseases, i.e. CVD, diabetes, respiratory diseases and cancers, is 21%. (World Health Organisation, 2014)

## **1.2 Diabetes**

Diabetes mellitus (DM) has become an emerging concern in public health. Diabetes mellitus is one of the most common and growing chronic non communicable diseases in the world which has serious medical and economic consequences (Shaw, Sicree, & Zimmet, 2010). The prevalence of diabetes is at a rise and so are the related multiple complications. The basic as well as clinical medical science has improved massively over the time, however diabetes mellitus still remains a lifelong disease which is incurable. The disease is seen to be increasing in both the genders as well as among all age groups. (Meo S. A., Diabetes Mellitus: Health and Wealth Threat, 2009) Diabetes involves various anatomical and physiological functions (Meo , Asim, & Khan, Risk assessment calculator for diabetic patients who fast during Ramadan, 2015) as well as body systems

(Vasilyeva, Frisina, Zhu, Walton, & Frisina, 2009). It is also known to be associated with devastating and wide ranging complications (James, et al., 2002). The associated conditions with diabetes are high rates of hospitalization, blindness, non-traumatic amputation and renal failure (American Diabetes Association, 1996). Globally there is a rise in the prevalence of diabetes mellitus in both urban as well as rural parts of the globe. In 2015, one in eleven persons worldwide are known to have diabetes and is expected to go to one in ten persons in 2040, with one in two persons with diabetes being undiagnosed (International diabetes federation, 2016). The prevalence of diabetes is expected to rise by 69% in developing countries and 20% in developed countries by the year 2030 (Shaw, Sicree, & Zimmet, 2010). There has been a rapid increase in the prevalence of diabetes in middle and low income countries (World Health Organization, 2016). The incidence rates of diabetes mellitus are also rising all over the world, mostly in the Middle East and South Asian countries. (Meo, Zia, Bukhari, & Arain, 2016)

Diabetes Mellitus (DM) has recently become a leading cause of high morbidity and mortality rates throughout the world (American Diabetes Association, 1996). According to World Health Organization (WHO) by the year 2030 the seventh leading cause of deaths would be diabetes (Mathews & Loncar, 2006). Latest data by the International Diabetes Federation shows that 5 million people die each year due to diabetes, which is more than the deaths caused due to HIV/AIDS, malaria and tuberculosis (Whiting, 2011). According to the International Diabetes Foundation (IDF) atlas, every six seconds a person dies of diabetes (International diabetes federation, 2015). The global health expenditure on diabetes alone is estimated to be 673 billion dollars, which is almost as much as 12% of the total health expenditure. This expenditure is yet expected to escalate as the pandemic progresses (Nijpels & Giel, Epidemiology of type 2 diabetes. Diapedia, 2016).

Pakistan is a country in the South Asia with a population of 193,204 million, making it the sixth most populous country in the world. It has an area of 796,095 km<sup>2</sup>, making it the 36<sup>th</sup> largest country in the world (The World Bank, 2016). Despite almost 60% of the population of Pakistan residing in rural areas, (Pakistan Bureau of Statistics, Government of Pakistan, 2017) Pakistan has been through significant economic and epidemiologic

transitions. Urbanisation has been on a rise in the country, which has led to various problems like sedentary lifestyle, more eating and less consuming, advanced calorie diet intake, and also the additional stressful conditions. All these have contributed greatly to the increasing prevalence of diabetes mellitus in the country. (Hu, 2011) Moreover exposure to polluted environment in urban areas of the country has led to metabolic disorders as well as diabetes mellitus.

Approximately 7 million people in Pakistan were estimated to be living with diabetes in 2014 (Hakeem & Fawwad, 2010). This figure was estimated to reach about 11.4 million by 2030 (Khuwaja, Khowaja, & Cosgrove, 2010). Pakistan is ranked 7th in the world for diabetes prevalence and one of the major causes for this ranking is the poor utilization of primary healthcare services. (Hakeem & Fawwad, 2010)

Overall in Pakistan, the mean prevalence of type 2 diabetes mellitus was found to be 11.77%. The prevalence of type 2 diabetes in the country has varied over time. Various studies have calculated the prevalence in various times and found that in 1999 the prevalence of type 2 diabetes mellitus 13.50%, in 2002 it was found to be 7.18%, in 2004 it was 9.52% in 2007 it was 8.74%, in 2009 it was 19.21% in 2010 it was 10.85%, in 2011 it was 10.95% and in 2014 it was 13.10%. The distribution of the mean prevalence in urban and rural populations of the country are 14.81% and 10.34%, respectively. The prevalence of diabetes mellitus type 2 in both the genders is; 11.2% in males and 9.19% in females. The mean prevalence of type 2 diabetes mellitus in different provinces of the country were: 16.2% among males and 11.7% among females in the province of Sindh, 12.14% among males and 9.83% among females in the province of Punjab, 13.3% among males and 8.9% among females in the province of Baluchistan; and 9.2% among males and 11.60% in females in the province of Khyber Pakhtunkhwa (KPK). The prevalence rate of type 2 diabetes mellitus has been at a gradual rise since the year 1995 till 2011. (Meo, Zia, Bukhari, & Arain, 2016)

Diabetes is a chronic condition which occurs when the body is unable to produce or use insulin, leading to raised glucose levels in the blood (known as hyperglycaemia). Disabling and life threatening complications are a consequence of high levels of glucose

in the body. There are three main type of diabetes which include Type 1 diabetes, Type 2 diabetes and gestational diabetes. Type 1 diabetes is due to an autoimmune reaction, in which the insulin producing beta cells in the pancreas are attacked by the body's defence system. Due to this the body is unable to produce the insulin it needs and therefore people with type 1 diabetes need insulin every day to control their glucose levels. Type 1 diabetes patients cannot survive without insulin. Type 2 diabetes is known to be the most common type of diabetes in the world. In type 2 diabetes the body is able to produce insulin but becomes resistant thus making the insulin ineffective. Insulin resistance and deficiency, both lead to high glucose levels. This type of diabetes is more common among adults but is now increasingly seen in children and adolescents too. This type of diabetes is the most common. Gestational diabetes is generally high glucose levels in pregnant women. It usually occurs from twenty four weeks in pregnancy (International diabetes federation, 2015).

### **1.2.1. Risk factors for type 2 diabetes**

There are various factors that contribute to the risk of having diabetes type 2. Some of these risk factors are age, obesity, gender, ethnicity, socio-economic factors, physical activity, diet, early life, environmental exposure and stress. Firstly the age is an important factor that leads to occurrence of type diabetes. There is a high prevalence of impaired fasting glucose (IFG) and impaired glucose tolerance (which are other indicators of disordered glucose metabolism) in people of older age. (National Institute of Diabetes and Digestive and Kidney Diseases, 2016) According to some estimates the chances of having a completely normal glucose metabolism after the age of 80, are almost 30%. (Nijpels & Giel, Epidemiology of Type 2 Diabetes, 2016) Such figures could also suggest that disordered glucose tolerance could not only be a disease but even be a part of normal ageing process. Secondly the major modifiable risk factor is known to be obesity (National Institute of Diabetes and Digestive and Kidney Diseases, 2016), with BMI<sup>1</sup> and the risk of type 2 diabetes having an exponential relationship. Most of the risk is

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<sup>1</sup> BMI: Body mass index (BMI) is a measure of body fat based on weight in relation to height, and applies to most adult men and women aged 20 and over.

explained by the central adiposity (Diabetes UK, 2017). So despite similar prevalence of diabetes in both the genders i.e. male and female, there are indications of increased risk in men as they have a greater distribution of adipose tissue in the center, as compared to women of the same BMI (Nijpels & Giel, Epidemiology of Type 2 Diabetes, 2016). Despite the indications that at same level it is also important to recognize that obesity itself indicates many metabolically unfavorable lifestyle factors, for example, intake of excess energy along with compromised physical activity (Nijpels & Giel, Epidemiology of Type 2 Diabetes, 2016). Despite the complexity in dissecting genetic factors from cultural lifestyle factors, certain ethnic groups seem to have a higher genetic risk of diabetes. Some ethnic groups that are known to have higher genetic risk of diabetes include the South Asians and the indigenous population of some regions, for example, the Aboriginals in Australia (Nijpels & Giel, Epidemiology of Type 2 Diabetes, 2016).

People from South Asian and the black-African descent have a two to four times increased likelihood of having Type 2 diabetes mellitus (Diabetes UK, 2017). However it is not all due to the genetic predisposition but also the influence of the affluence on this predisposition of genetics, which helps to explain the comparatively latest rise in the prevalence of diabetes in these groups. The socio economic factors also seem to influence the risk and prevalence of diabetes in various areas. Out of every three patients of diabetes, two are living in urban areas. Also there is a disproportionately increased effect on the lower socio-economic classes. Although the reasons behind these are still not clearly understood, however an important mediating factor could be their unhealthier lifestyle. Recent economic growth and urbanization in the lower middle income countries around the globe, have led to their larger contribution to prevalence of diabetes possibly due to recent changes in lifestyle and longevity (Nijpels & Giel, Epidemiology of Type 2 Diabetes, 2016). Physical inactivity is also known to be a risk factor for type 2 diabetes mellitus (Joslin Diabetes Center, 2017). The physical activity is known to have favorable effects on glucose metabolism as well as on the risk of getting obese. However the risk factor is total lack of any activity which is a sedentary lifestyle (Fleckenstein, 2016), rather than the absence of high level physical activity at the population level. Especially there have been obvious associations between risk of becoming obese and sedentary



behaviors, for example, watching TV. Evidence shows that the best strategy to prevent diabetes has been dietary interventions i.e. restricted intake of calories, along with increased physical activity. This seems to be quite understandable as there is a strong relationship of diabetes with obesity. Also not only the caloric intake but certain diets are known to be a risk factor for diabetes. Recently we have seen that sugar sweetened drinks are likely to increase the risk of having diabetes. However study on diets is a complicated phenomenon as people with healthy diets also have many other healthy behaviors that could be affecting the results. Recently it has been found that a person's early life (as early as the fetal stage) could also influence the risk of them having diabetes in later stages. Earlier the birth weight was associated as a major risk factor for having diabetes but recently studies have found that more subtle factors may have a vital role in contributing to the risk of having diabetes. These subtle factors could include minor things such as deficiency of micronutrients during the early life of a person. There are many environmental pollutants/ toxicants that are also known to be a risk factor for type 2 diabetes. Although studies regarding some harmful bio chemicals being a risk factor diabetes type 2 are found to be a risk factor for type 2 diabetes in studies on animals, however in the humans they are inconclusive and therefore more research in this area is required. Studies have also repeatedly shown a relationship between lack of sleep and working in shifts with the risk of having type 2 diabetes. However it is not yet clear whether this relationship is due to biological clock being disrupted or due to stress. There is a well-known glucose raising effect of the main hormones released in stress i.e. cortisol and adrenalin. There are clear evidences of having a short-term increase in glucose levels as a reaction to stress. However there is still no epidemiological evidence to support the relationship between long-term stress and the risk of having type 2 diabetes (Nijpels & Giel, Epidemiology of Type 2 Diabetes, 2016).

### **1.3 Health Services Context**

In Pakistan, due to the 18th amendment the services related public sectors including health sector have gone through devolution in 2011. In consequence of this the Federal Ministry of Health (MoH) has been dissolved thus making the provincial governments responsible for the health services policy direction and planning (WHO, 2016).

Punjab province has a population of more than 110 million people. The province is further segmented into thirty six districts. (Pakistan Bureau of Statistics. Government of Pakistan, 2017) It is the responsibility of the provincial government to plan, finance and deliver health. At district level, the public infrastructure for delivering health care comprises of district and sub district (tehsil) level hospitals and rural health centres. These hospitals and health centres have doctors and other associated/ allied professionals and also have basic labour facilities. A district health office is responsible for managing public funded care at these secondary and primary level health facilities. Primary care for diabetes in Pakistan is delivered through a network of (sub) district (i.e. ‘Tehsil’) hospitals and health centres. The managing and provision of primary care related to diabetes is the responsibility of the District Health. The hospitals and health centres are in principal supposed to have the necessary testing facilities e.g. for blood/urine as well as the needed drugs for the prevention and management of diabetes. However, in reality the supply of drugs and equipment is not regular in these facilities.

#### **1.4 Diabetes prevention and control-related efforts in Pakistan**

Pakistan in 2003, framed a National Action Plan for NCDs prevention, control and health promotion through public private partnership (Nishtar, Prevention of non-communicable diseases in Pakistan: an integrated partnership based model, 2004). However World Health Organization has declared national systems response to NCDs as very poor. Operational multi-sectoral national policy, strategy or action plan for integration of various NCDs/ related risk factors; promotion of physical activity and healthy diets are all lacking in Pakistan. There is a lack of evidence-based national protocols/ standards/ guidelines to manage NCDs. Pakistan also does not have any NCD surveillance and monitoring system in order to report against the nine global Non communicable disease targets. Therefore all these factors combined lead to the failure of our national action program for Non communicable diseases in achieving its targets (World Health Organisation, 2014).

However, in Pakistan most of the work for prevention and control has been done for Diabetes as compared to for other NCDs. Diabetes Association of Pakistan (DAP) was

made in 1966. In 1967, the association was affiliated with International Diabetes Foundation (IDF) (Diabetic Association of Pakistan, 2016). Since its establishment DAP has played a part in improving the care and prevention of diabetes in Pakistan. DAP has played a role in the launch of the first four national diabetes action plans. These plans were made in 1996-98, 1999-2001, 2001-2004 and 2005-2009.

The conceptualization of the first National Action Plan on Diabetes was done in 1995. This plan was conceptualized on the basis of the conclusions drawn from the National Workshop held in Islamabad in November 1995, on Diabetes Control. An epidemiological survey highlighted the magnitude of the disease which led to the evidence based necessity for developing the Diabetes Plan. In the first diabetes plan, based on principles that were scientifically valid, it was recommended to develop a primary prevention programme for diabetes. The plan also emphasized on the need to improvise the management of persons who have diabetes. Furthermore the plan suggested integration of diabetes with the other non-communicable diseases and as well as with the primary healthcare, training the healthcare staff, an additional effort to step up the data collection regarding the disease, development of tools that are customized as an identification and priority of high risk groups with the use of mechanisms that are integrated, for example, as in case of the gestational diabetes, giving health education to the people.

There were also strong recommendations for the Ministry of Health to work out a feasible as well as effective mechanism to make sure that the ministry plays the role as an initiator as well as a coordinator of activities related to diabetes prevention, with active contribution of the private sector stakeholders. It also brought forward the need for appointing of a focal point for Non Communicable Diseases in this regard.

The second diabetes plan was made for the period of 1999 to 2001. This plan updated the objectives as well as the strategies for diabetes care, reviewed the progress of the first plan in terms of the activities and also proposed additional initiatives for the said period. The preparation of the revision was based on discussions held in March 1999, in Karachi, Pakistan. The Second Plan made a precise recommendation of adopting the World Health

Organization standards of care along with a reemphasis on the recommendations that were made in the first Diabetes Plan. There was some success of these diabetes plans, with regard to developing some clinical guidelines on how to manage diabetes, as well as obtaining a changeover to unified strength of insulin. However a prerequisite to any Plan of Action is it being modelled in an area of demonstration, as well as integrate a protocol for evaluation, in order to be able to refine the important elements and become able to apply to wider settings the lessons that were learnt. These Diabetes Plans packaged outcome measures related to morbidity which were projected over a long term. However there was no clear definition of processes and output measures on a short term to medium term.

An attempt to bridge the gaps of the two Diabetes Plans was made by putting forward another action plan known as the National Action Plan for prevention and control of non-communicable diseases and Health Promotion in Pakistan (NAP-NCDs). Moreover this action plan integrates the prevention of diabetes with the other non-communicable diseases. This approach is highlighted by the Integrated Framework for Action (IFA). This Plan comprised of an action agenda specifically for the diabetes disease. The action plan recommended for diabetes care included firstly integrating the diabetes surveillance with a comprehensive population based non-communicable disease surveillance system; which is in short term assessing risk of diabetes using the waist circumference (as a proxy indicator) and for long term upgrading the surveillance to do a more comprehensive assessment which could incorporate biochemical assessments; building on the previous data collection methods; as well as integrating the monitoring and evaluation of the public health programme with the NCD surveillance. Secondly it recommended the integration of diabetes prevention as a component of the wider communication strategy of behavioral change. Thirdly it recommended that the health systems capacity needs to be further built and strengthened in a way which support the prevention as well as the control of type 2 diabetes mellitus. Fourthly the plan recommended the integration of diabetes prevention as well as intensified case finding in the groups that are high-risk into the health services as a component of a detailed, sustainable, scientifically correct, culturally suitable and resource sensitive CME programme for healthcare providers of all

categories. The plan also recommended that the availability of essential drugs for diabetics (e.g. insulin, sulphonylureas<sup>2</sup>, metformin<sup>3</sup>) should be ensured at every level of healthcare. The plan further recommended to learn from and further build on the already done efforts in Pakistan, that were scientifically valid, in relation to preventing and controlling diabetes. The plan further recommended that in order to further strengthen and give pace to diabetes prevention and control as a part of a comprehensive NCD prevention effort, there is a need to make build a network of national, provincial and local level organizations which are facilitated by the federal as well as the provincial health services. ( Pakistan: tripartite collaboration of the Ministry of Health, Government of Pakistan; WHO, Pakistan office, and Heartfile, 2004).

However these national diabetes action plans have been reported to not being fully implemented (according to the International Diabetes Federation). IDF has also declared that the health services provided by the health systems for diabetes and the government funding are not enough because of budget limitations as well as inadequate distribution of the funds available (International Diabetes Federation, 2016). Other than DAP, Pakistan Endocrine Society (established in 2001), National Association of Diabetes Educators of Pakistan and some Diabetic Institutes and other groups have also contributed in the improvement of care and prevention of diabetes in Pakistan (Sherin, 2015).

Pakistan has recently developed a National non communicable disease program, with the support of IDF. The Provincial NCD and Mental Health Program has been made to cater the unmet need of prevention and control of NCDs in Punjab. The Program is relatively new not just in Pakistan but also throughout the world. Therefore there is a need for standardized care packages to be developed and tested that are also culture-sensitive.

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2 Sulphonylureas: A class of oral hypoglycemic agents (medications that lower the level of blood glucose) taken by people with type 2 diabetes. The sulfonylureas increase the secretion of insulin by the pancreas.

3 Metformin: An antidiabetic drug used in the form of its hydrochloride  $C_4H_{11}N_5 \cdot HCl$  especially to treat type 2 diabetes in patients unresponsive to or intolerant of approved sulfonylurea drugs.

The province of Punjab has become the pioneer in taking measures to incorporate an integrated diabetes care into the public-funded hospitals and health centres/ facilities. The Directorate General Health Services (DGHS) Punjab, along with the support of other technical and development partners, undertook an intervention development and evaluation activity in order to deliver integrated diabetes care at primary as well as secondary level health facilities.

A pragmatic cluster randomized controlled trial (as a pilot intervention) was conducted to assess the effectiveness of a package of diabetes-cardiovascular disease care delivered through rural primary healthcare facilities (PHC) in Pakistan. The randomized controlled trial was conducted in Sargodha district of Punjab, Pakistan, with diabetes patients recruited (on routine/normal diagnosis process) into intervention and control arms, each with seven primary healthcare facilities, from August 2014 to June 2016. It assessed whether levels of HbA1c, and other parameters such as random blood glucose, fasting blood glucose, serum cholesterol, systolic blood pressure, diastolic blood pressure, urine protein, etc., differed between the arms after 9-months from the time of recruitment. HbA1c and serum cholesterol were only done twice which is at the registration time and at the end of 9 months. A standardised care package for diabetes was developed. The trial was conducted through the doctors and paramedics<sup>4</sup> at public health facilities in the primary health centres/ facilities. The cluster randomized controlled trial was conducted by a public health approach which included the standardisation of procedures that would enable systematic care. This systematic care included firstly the screening of patients with potential risk of having diabetes. This risk group especially included those who were overweight and thus were more likely to have diabetes. The newly diagnosed diabetics were registered in the trial after taking their consent to participate in the research. Various physical as well as medical assessments were done at registration. The patient's data was collected on a non-communicable disease card (NCD). This NCD card was exclusive for

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<sup>4</sup> Paramedic: The paramedic is responsible for the assessment and management of the patients, and giving them medical care in the prehospital setting, that involves interventions, such as the administration of medications. For this, a paramedic needs to know all the medications in the formulary that their regional protocols include. (Bob Elling, 2009)

every patient registered and was used for recording the patient's data throughout the trial period of 9 months.

The NCD card recorded the data collected at registration as well as the following 8 monthly follow up visits. At registration time data was collected regarding where they live, number of schooling years, family income, age, height, weight, random blood glucose<sup>5</sup> or fasting blood glucose<sup>6</sup>, HbA1c<sup>7</sup>, serum cholesterol<sup>8</sup>, urine protein<sup>9</sup>, systolic blood pressure<sup>10</sup>, diastolic blood pressure<sup>11</sup>, treatment regimen given to the patient as

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5 RBG (Random Blood Glucose): A random blood glucose test may be performed at any time, regardless if a person has fasted or not. This is a simple test during which a sample of blood is drawn from the arm and is sent to laboratory to measure the level of blood glucose. In general, blood glucose levels of 200mg/Dl or higher are suggestive of diabetes. (Jacob, 2012)

6 FBG (Fasting Blood Glucose): A fasting blood glucose is performed on a blood sample taken when the patient has not eaten for a specified period of time. A fasting specimen is usually obtained before breakfast after the patient has gone without food since the previous evening's meal. (Norma J. Walters, 1986) The diagnosis of diabetes is based on the presence of blood glucose concentrations equal to or greater than 126 mg per 100 ml (7.0 mmol per litre) after an overnight fast. People with fasting blood glucose values between 100 and 125 mg per 100 ml (6.1 to 6.9 mmol per litre) are diagnosed with a condition called impaired fasting glucose (prediabetes) (Cauz, Encyclopædia Britannica, 2010)

7 HbA1c: HbA1c (A1C), is a measure of long-term glycaemic control, and is used to monitor clinical treatment in persons with diabetes. (Elizabeth Selvin, 2006)

8 Serum Cholesterol: It is a composite of different types. A person's total serum cholesterol score is calculated by adding the high-density lipoprotein (HDL) and low-density lipoprotein (LDL) cholesterol levels and 20 percent of their triglyceride level.

9 Urine Protein: A urine test that detects tiny amounts of protein. (Clinic, 2014) Healthy individuals excrete very small amounts of protein in the urine (about 80-100mg of protein per day). In the presence of kidney damage, larger amounts of protein may be excreted. Increased excretion of albumin is associated with diabetic nephropathy, glomerular disease, and hypertension. Clinical proteinuria is defined as the loss of >500mg/day of protein urine. (Lee M. , 2004)

10 Systolic Blood Pressure: Systolic pressure is the maximum blood pressure during contraction of the ventricles. While calculating the blood pressure, the systolic pressure is usually written over the diastolic pressure e.g., 120/80 mm Hg (H Kenneth Walker, Clinical Methods: The History, Physical, and Laboratory Examinations. 3rd edition., 1990)

11 Diastolic Blood Pressure: The diastolic pressure is the minimum pressure recorded just prior to the next contraction. While calculating the blood pressure, the diastolic pressure is usually written

prescribed by the doctor, smoking status. As a first step every newly diagnosed patient of diabetes registered in the trial was supposed to be given education on lifestyle modification which primarily included modifications in diet, physical activity and tobacco use. Further the medical treatment was also provided as and when needed. This treatment included a standardised treatment for all patients which was divided into steps which were based on intensity of uncontrolled diabetes. The treatment also ensured free drugs being available to patients. Although anti diabetes are already a part of the essential drugs list provided by the government at the public health facilities but they are not readily available at the public health facilities. The trial ensured that the anti-diabetic drugs were available at the public health facilities free of cost for all registered patients. The patients were expected to come to the public health facility every month for a follow up visit. At the follow up visit again the patient was assessed for weight, random blood glucose or fasting blood glucose, urine protein, systolic blood pressure, diastolic blood pressure, and this information as well as the treatment (medication and lifestyle change) recommended to patient as prescribed by the doctor, and the patient's current smoking status was also recorded in the patient's NCD card. The doctor was responsible for assessing patient as well as giving treatment along with some (generic) lifestyle counselling. However the paramedic of the public health facility was mainly responsible to maintain NCD cards of every patient registered in the trial and check for completeness of patient data as well as provide detailed lifestyle counselling to the patients (with the help of flip tool). The patients were also given adherence support by giving a recall to patients for follow up through SMS being sent to them as a reminder of their follow up visit being due in the coming day or two. The patients who did not show up for follow up visits or whom the paramedic felt needed a reinforcement were also called to remind them about their due follow up visit. The patients were also given appropriate referrals to district headquarters hospital, in case they needed further diagnosis/ treatment.

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below the systolic pressure e.g., 120/80 mm Hg (H Kenneth Walker, Clinical Methods: The History, Physical, and Laboratory Examinations. 3rd edition, 1990)



The trial then assessed the mean differences in glycaemic control in the type 2 diabetes adult patients who received quality care for diabetes (from standardised evidence-based guideline based care) as compared to those receiving routine care at the public health facilities. The standardized care package developed through DGHS-led technical working group included:

1. case management desk guide
2. material to train doctors and allied staff
3. Flipbook (pictorial tool) for lifestyle counselling
4. Flipbook (pictorial tool) for tobacco cessation

#### **1.4.1 Intervention care package**

The trial facilitated the routine care with the development of operational guidelines including desk guide, training modules (for care providers i.e., doctors and paramedics) and counseling tools. All type 2 diabetes patients of both genders with age > 25 and resident of the catchment area of the respective health facility were included in the trial.

There are total 153 health facilities in district Sargodha as tabulated below:

Table 3: Type and Number of Health Facilities in Sargodha

<b>Type of Public Health Facility</b>	<b>Number</b>
District Head Quarters Hospital Sargodha (DHQ)	01
Government TB Hospital Sargodha	01
Tehsil Head Quarters Hospitals (THQ)	06
Rural Health Centers (RHC)	12
Basic Health Units	117
Civil Dispensaries	08
Mother and Child Health Centers	08
<b>Total</b>	<b>153</b>

The district team grades each health facility through multi indicator tool every year, especially on two basic accounts as mentioned below:

1. Working/functioning of health facility
2. Professional commitment of staff (Doctors and Paramedics)

As per the latest grading (of District Health Information System), rural health center 104 NB falls in 'A' Grade along with other thirteen health facilities (five tehsil headquarters hospitals and nine rural health centers) included in the pilot intervention (both for intervention and control arm). The name and grade of the health facilities are tabulated as followed:

Table 4 Name and the Grade of the Health Facilities included in Intervention

<b>Name of the public health facility</b>	<b>Grade (as per District Health Information System (DHIS))</b>
THQ hospital <i>Bhalwal</i>	A
THQ hospital <i>Sahiwal</i>	A
THQ hospital <i>Chak No. 90-SB</i>	A
THQ hospital <i>Bhagtanwala</i>	A
THQ hospital <i>Kot Momin</i>	A
RHC <i>Miani</i>	A
RHC <i>Bhera</i>	A
RHC <i>Phullarwan</i>	A
RHC <i>Lilliani</i>	A
RHC <i>Bhabra</i>	A
RHC <i>Chak No. 104-NB</i>	A
RHC <i>Sillanwali</i>	A
RHC <i>Farooqa</i>	A
RHC <i>Jhawarian</i>	A
THQ hospital <i>Shahpur</i>	B
RHC <i>Midh Ranjha</i>	B

RHC <i>Chak</i> No. 46-SB	B
RHC <i>Moazamabad</i>	C

The pilot intervention used a desk guide and two tools (one for lifestyle change and one for smoking cessation) in the seven intervention health facilities including two tehsil headquarters (THQ) and five rural health centers (RHC).

The study locale (*Chak*<sup>12</sup> 104 *Shumali*<sup>13</sup>) were able to register 71 patients of diabetes (in the first phase of pilot intervention) that outnumbered other health facilities (in terms of patient's registration without any outreach and were diagnosed as routine/normal). The health facilities used the desk guide as a standard guideline for the below mentioned:

1. Diagnosis
2. Treatment
3. Follow up

The desk guide was developed by directorate general of health services Punjab Pakistan (non-communicable diseases and mental health) in consultation with Association for Social Development, Pakistan and Nuffield institute for international health and development, University of Leeds UK. The desk guide was technically guided by World Health Organization, Punjab Pakistan and supported by UK aid and DFID<sup>14</sup> UK (through communicable disease research programme – health service delivery).

The desk guide, as a decision aid, does not cover all possible situations and/or solutions related with the management of type-2 diabetes and hypertension-CVD. The clinical

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12 Chak: An agricultural field, so a village. (Sasaki, 1978). The villages are named using a certain nomenclature that dates back to British rule; all names are prefixed "Chak" followed by a number and a letter. The number is the name of the village and the letter relates to their source of water.

13 Shumali: Northern, Northbound

14 DFID: The Department for International Development (DFID) is a United Kingdom government department responsible for administering overseas aid. The goal of the department is "to promote sustainable development and eliminate world poverty". DFID is headed by the United Kingdom's Secretary of State for International Development.

management of the doctor remained the basis for final decision making and this aid was only taken as a supplement and not a substitute of the clinical acumen. The desk guide contents was based on international guidelines, which have been contextualized to the operational circumstances, through in-country working group process. The main guidelines consulted for the exercise included below mentioned:

1. WHO (2007): Prevention of cardiovascular disease – Guidelines for assessment and management of cardiovascular risk
2. NICE (2011): Clinical management of primary, detection, evaluation and treatment of high blood pressure
3. IDF (2005): Global guidelines for type-2 diabetes
4. NICE (2009): The management of type-2 diabetes

The desk guide provide guidelines for the clinical investigation and diagnosis of type-2 diabetes and hypertension that included:

1. Investigate if appears to be overweight (a weight chart was annexure with the desk guide as per height and gender of the adult patients).
2. Investigate for family history
3. Investigate for complaints including increased thirst and/or hunger and/or frequent urination. Also for recurrent infections, thrush, skin boils<sup>15</sup>; feel of pins and needles in feet. Also for feeling tired or difficult to concentrate and blurred vision.

The baseline assessment also included associated conditions, smoking status, eye complaints and pregnancy.

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<sup>15</sup> Skin boils: A boil (furuncle) occurs most often in the dense dermal connective tissue at the back of the neck. The causal organism *Staphylococcus aureus*, invades via the hair follicles or sebaceous ducts and sets up an acute inflammatory swelling or a lesion caused by the accumulation of pus or dead tissue. Furuncles are more common in diabetics. (Muir, 1951)

The interesting part of the desk guide was regarding the guidelines to inform the patients regarding the below mentioned after being diagnosed and labeled as a diabetic:

1. It requires lifelong management
2. Affects the longevity and quality of life
3. Requires management (including drug intake and healthy lifestyle change – that was further explored as a complex process itself in the present study)
4. Refer patient(s) to the designated paramedic for lifestyle counseling session (explored further in detail through present study)

A further set of guiding principles were mentioned to treat patients through lifestyle change and a step by step drug regimen considering any associated conditions. A clear action based on four steps are guided to administer the drugs (keeping in view the variation in situations of the patients).

A separate section was also presented for monthly follow up checkups (for continued treatment). A minimum of four follow up visits (excluding the registration) were considered to be essential for a patient to be categorized as adherent to the treatment. The follow up checkup included clinical investigations, asking about adherence to the prescribed drugs and adherence to the lifestyle (further through the designated paramedic) and further prescribing any changes in drugs if required.

The lifestyle counseling tool was also developed by the Programme as mentioned above as well. The prevention and control of non-communicable diseases and mental health team developed it in consultation with national and international partners.

The tool has ten slides in total with different important messages in local (Urdu<sup>16</sup>) language. The tool was piloted and the paramedic was trained accordingly to counsel the

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16 Urdu: Urdu is the national and official language of Pakistan. It is written in a modified version of the Perso-Arabic script, and written and read from right to left. It is an alphabetic script whose letters include thirty-three consonants taken from the Persian alphabet, as well as three new letters that represent retroflex sounds, and eleven compound letters that represent aspirated consonants. (Chaitra Rao, 2010)

patients. The piloting of tool also assessed time required for counselling (how many minutes will it take to go through the ten slides per patient). There was seen a slight variation in timings of counselling sessions with patients however the overall average time was similar.

The important messages included introduction to diabetes and high blood pressure; causes of diabetes or that may create further complications; problems that may arise due to diabetes and high blood pressure; treatment of/for diabetes; management of diabetes; and details of healthy diet and healthy lifestyle. Whereas, the smoking cessation tool has nine slides. The slides offer five steps to quit smoking to those registered patients who were identified as smokers.

## **1.5. Problem Statement**

The Punjab Non Communicable Diseases (NCD) and Mental Health Programme has developed a contextualized intervention to manage Diabetes and Hypertension at primary health care. Doctors and paramedics have been trained to manage with a given regimen and lifestyle counseling. Research shows that the effective management of lifelong diseases, such as diabetes, is highly dependent on the socio-cultural context of the patients. The clinical management and lifestyle modification is complex and may require an in-depth understanding of the lives of the diabetics. The diagnosis, labelling, follow-up, change in diet, physical activity and smoking is a product of certain socio-cultural factors that may act as enablers or barriers towards adherence to the treatment of type 2 diabetes.

Therefore there is a dire need to study in detail the cultural context of Punjab to create a more detailed understanding of effective management of the disease. A detailed qualitative understanding of the cultural context will further help the NCD programs to refine the management of diabetes in the province in a way which is more socio-culture-sensitive.

## **1.6. Objectives of the study**

The department of health Punjab has started offering diabetes/ hypertension care to rural and urban populations through public health facilities. The care has two main components i.e. diagnosis & treatment and life style change. The department has shown interest in enhanced understanding of the life style practices and adherence to the clinical treatment (especially follow-up), so that intervention can be further sensitized to these contextual realities. The response towards life style modification education and treatment plan can actually help in management of the disease and also help in prevention of serious complications. The pilot intervention is under the process of getting up scaled in the province of Punjab. The pilot intervention holds a significant say in understanding the overall care package offered and received (by the target population). The patients' perspective is also substantial in the smooth execution of the diabetes care package. The diabetes care package is a mix of both clinical and socio-cultural understanding(s). The beyond clinical realities may be considered as an important dimension in further implementation and troubleshoot issues related to the adherence towards the diabetes care package. The type 2 diabetes lifelong management demands to contextualize the care package offered (especially at the primary health care level). The current study was designed to explore the socio-cultural factors that may help understand the issues (especially barriers) related with the diagnosis, treatment and adherence to the proposed treatment (both clinical treatment and lifestyle modification). The adherence towards the treatment of type-2 diabetes is not just important in the prevention of developing co-morbidities and further complications but also in the effective and efficient management of the known cases.

The adherence to the proposed treatment is indeed an important dimension to explore, that may explore and explain the socio-cultural barriers that may be helpful in making the diabetes care package more contextualized with the local settings of Punjab. The current study focused on the episode of diabetes (that a patient in its respective community goes through) with a special focus on the adherence to the proposed treatment. The current study was designed as one of its own kind research to contextualize the diabetes care

package (in case of Punjab province). The providers at primary health care level and relevant programmes may also get a further understanding of the in-depth aspects of adherence (in general) that may lead to efficient and effective prevention and management of the identified cases. The main objectives of the study are:

1. To explore the experience and perceptions till the diagnosis of diabetes disease and reaching the health facility;
2. To explore the socio-cultural factors specifically influencing the clinical treatment (i.e., diagnosis, prescription and follow-up);
3. To explore the socio-cultural factors specifically influencing the lifestyle modification (i.e., diet, exercise and smoking cessation)
4. To explore other factors influencing the overall treatment of type 2 diabetes.

## **1.7. Rationale**

Before the 19<sup>th</sup> century the focus of public health has been on what was causing the morbidity, mortality, injury or disability. Later in the 19<sup>th</sup> and early 20<sup>th</sup> century, public health shifted its focus to the physical environment, such as supply of clean water; safe housing, workplace, and food; sanitation etc., which led to considerable rise in average life expectancy of people (CDC, 1999) (CDC, 1999). In the later decades of the 20<sup>th</sup> century the focus was shifted on expansion of access to medical care which led to an increase in life expectancy especially after the age of 65. (Cutler, Rosen, & Vijan , 2006) However in the recent decades public health has learnt that more than the medical care of a person, the social and economic factors determine the health of the population as well as how it further affects health differences in health of various subgroups. (Institute of Medicine , 2002)

In a recent research the health of a population was found to be determined: ten percent by the physical environment, twenty percent by the clinical health care i.e. the quality and access to care, thirty percent by the person's health behavior for example lack of physical activity, and forty percent by the social as well as the economic factors. (Booske ,



Athens, Kindig, Park, & Remington, 2010) The social and economic factors along with being the major determinants of the population's health themselves also have a huge impact on the second largest determinant of health that is the health behaviors. The more supportive the social environment is the more are the chances of having healthy behavior. (Los Angeles County Department of Public Health, 2013)

Therefore, many factors are together known to be responsible for the health of individuals as well as communities. The circumstances as well as the environment of the people determine whether they are healthy or not. It has been found that the more commonly known factors such as the access as well as the use of health care services more often have a smaller role in determining health. However to a huge extent, other factors for example living area, level of education, income, genetics, relationship with the friends and family, the state of our environment all play a significant role in determining health. According to World Health Organization the determinants of health include the social and economic environment, the physical environment, and as well as the individual characteristics and behaviors of the person. The health of a person is known to be determined by the context of their lives, therefore it is seen to be inappropriate to hold responsible solely the individuals for poor health or vice versa assuming that good health is a credit of the individual alone.

Many of the factors that determine health are unlikely to be controlled by the individual person. Further, more determinants that are known to affect the health of individuals are following:

1. Level of education is directly linked with health condition. The lower education levels are likely to cause poor health, lower self-confidence and more stress.
1. Social status and income of the patient is directly proportional to being healthier. The wider the gap between the poorest and richest people, the greater would be the differences in health.
2. Physical environment plays a significant role. Good health is a by-product of clean air, safe water, safe houses, communities and roads as well as healthy

workplaces with more control over working conditions are likely to cause better health.

3. Social support networks determine health, as more support from the families, friends and communities is likely to lead to better health. Health is affected by the culture; traditions, beliefs and customs of the family as well as the community.
4. Genetics as well as personal behavior also determine the health. Healthiness, the probability of developing certain diseases as well as the lifespan could be affected by inheritance. Other personal behaviors such as balanced diet, physical activity, tobacco use, drinking, and how we cope with stress and challenges also affect health.
5. Health services available also influence the health of the people. The access as well as the use of preventive and curative services for diseases also has an influence on health.
6. Gender is likely to affect health in various ways. Typically men and women have different types of diseases at different ages. (World Health Organization, 2017)

It is a known fact that in order to improve medical care, a more in depth understanding and knowledge of local cultures is a must (Glover, 2009). Realizing the impact of the various other factors on health, it seems to be essential that to ensure the success of any health intervention it is a prerequisite to study in detail all the possible determinants that could affect the health intervention. It is therefore necessary to understand the socio-cultural factors that are likely to play a vital role in determining the health of the patient, along with the treatment given to the patient for the disease care. Diabetes being a lifelong disease needs management for life. (International Diabetes Federation, 2013) Therefore any intervention designed for care of such long term disease should be sensitive to the socio-cultural environment of the population. This study is therefore an attempt to understand the socio-cultural factors that could affect the adherence of the diabetes patients to the care being suggested in the intervention and to come up with the

enablers and constraints that lead to people adhering with the care package being recommended.

The diabetes care package requires skill mix beyond medical knowledge i.e., the counseling tool for life style modification and treatment adherence needs to be refined and understood (socio-culturally) along with province-wide scaling. The hypertensive conditions are known to have substantial association with individual life style i.e. diet, exercise and smoking. As lifestyle is a product of multiple socio- cultural, psychological and economic factors, so any effort to change the lifestyle requires more in-depth understanding of lay belief systems, cultural norms, access to information and products, social service context etc. Thus, by studying the impact of the treatment plan and lifestyle education to registered diabetics has added to the knowledge of primary health care regarding diabetes prevention and care in Punjab, Pakistan.

The pilot intervention proposed a biomedical process of diagnosing, labeling, counseling and following up of the diabetics. The provider's perspective (at primary health care level) is mentioned above in detail where both physicians and paramedics were involved in identifying and managing the diabetics in their respective catchment areas.

The pilot intervention on the other hand, required patient's perspective on the same above mentioned issues of diagnosis, treatment and challenges to lifestyle change. The intervention designed and implemented as pilot before scale up at provincial level may require the community (especially target population) perspectives that may be used as general suggestions/recommendations towards certain processes of diagnosis and treatment at large (that included medication and lifestyle change).

The patient's perspective as a special focus of this study may not only inform the national and provincial programmes (and their partners) but may be considered as one of its own kind research towards understanding the diabetes (as an illness). The proposed treatment was a biomedical construct that may also be understood from patient's angle and their respective problems, fears, challenges and socio-cultural factors at large that may influence or compromise the adherence towards the proposed treatment of diabetes. The

adherence to the proposed treatment implemented through pilot intervention in selected health facilities, thus may be seen from the patient's perspective as an explanatory models of illness (of/for diabetes).

## **1.8. Significance of the study**

The 'National Action Plan' for prevention and control of non-communicable diseases and mental health promotion in Pakistan holds a significant action agenda (with priority action areas) for diabetes (in specific). Both prevention and control of diabetes is not just relevant but becoming a dire need for the Action Plan to fill the void between academic researchers and administrators and policy makers for the overall betterment and improvement in health outcomes by developing evidence based strategies.

The current study also holds a significant relevance as there is hardly any diabetes interventional trials run/conducted in the native settings of Punjab, Pakistan (and was never used as an entry point for Anthropological study of a Punjabi village). The diabetes care does demand a strong research support to understand the perceptions and adherence (at large) towards the proposed treatment (in local settings). The lifestyle change as a buzz word offers more subjectivity (when seen from the lens of Anthropology). The subjective nature of understanding the proposed lifestyle change makes it an area of socio-cultural investigation(s) for design, implement and upscale.

The prevention of diabetes (at primary health care level) is grouped into two major approaches including 'population approach' and 'high-risk approach'. Both approaches seek support from Anthropological perspectives as they are a mix of clinical and socio-cultural dimensions. The training of the physicians and non-physician health care providers may include findings (case studies and themes) from the socio-cultural viewpoint to successfully design and implement the modifiable risk factors and addressing risk factors along with intensified case finding and effective and efficient management. The study may also add to the academic literature and knowledge in Medical Anthropology. It is also cross cutting with various issues of/in Anthropology including development, gender, cognition and social processes.

The National Action Plan also did demand a need to address the training packages (that may be locally relevant and implementable). The training of the health care personnel (in context of the present study) may also enhance the quality of patients' education towards management of type 2 diabetes and better adherence rate. It is also important to mention that the current study may hold a significant position in explaining the diabetes care package (from the patients' perspective) to the national programme and provincial teams. The wider socio-cultural findings not only address the gaps in poor adherence but may also suggest areas that could be seen from local dimensions (of understanding, absorbing, accepting and practicing the diabetes care package).

The current study goes beyond the clinical understanding of diabetes care and its adherence (especially in the rural village of Punjab). The study may suggest contextual understanding of the care package including how diabetes care may be seen with the socio-cultural construction (of the disease). The adherence towards proposed treatment may also be seen as an operational socio-cultural reality experienced subjectively by the patients. The study also brings forward the barriers in process of adhering towards the proposed treatment including culturally endorsed support treatments and alternate treatments. Both the prevention and management of the diabetes may be seen as a complex structure that may include a large chunk of socio-cultural factors that may affect and influence the adherence towards the diabetes care package. The local perspective not only enhances the knowledge level but also provides traces to manage the known cases effectively and efficiently.

The explored socio-cultural factors as themed in different dimensions provided a knowledge-full structure (that may also be seen as a journey with diabetes). The journey includes various perceptions and practices (that may be generalized for similar environments and socio-cultural settings). The adherence to the medications and lifestyle reflected a strong relationship with subjective conceptualization of diabetes and its lifelong management. The similar explanations to the various issues in the episode of disease made certain decisions visible in the context of the *Chak 104 Shumali*.

The current findings (especially adherence to the proposed diet and exercise) may be useful in the design and implementation of prevention strategies and also management of high risk population (of similar context). It may also be recommended that the ‘free of cost’ treatment may lead to a very different perception and perspectives by the patients. The cost was also found to be a socio-cultural construct and may not be a significant factor in the success of the design. The culturally crafted access, ease and economy may decide the fate of the design. The local culture also creates habits of a local lifestyle (that may be confusing and subjective with the proposed care package) such as obesity may not considered fat or unhealthy, the diet is mostly tilted towards taste instead of health benefits, exercise may be confused with work and house chores.

The study is also unique that may address the training modules for the physician and paramedic to introduce and implement better patient provider communication and lifestyle counseling in particular. The study also reflect an in-depth understanding and substance for creating a framework to troubleshoot issues in a localized manner especially in the follow up sessions.

The study is also relevant to International Diabetes Federation whose road map has been used to design and implement the diabetes care in Punjab. It is also an important study for the economies in transition and still hold rural urban dichotomy. The developing economies with similar settings may also gain in depth understanding of the patient’s perspective while designing diabetes management packages. The implementation partners and public health agencies in particular may also be an audience to the findings of the study.

The pilot intervention implemented at primary health care level was done under the COMDIS-HSD17 consortium which comprises of country partners from low and middle-income countries including Nepal, Bangladesh, Pakistan, Swaziland and Ethiopia. The coordinating partner for COMDIS-HSD is The Nuffield Centre for International Health and Development, University of Leeds (UK).

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17 COMDIS-HSD is a Research Programme Consortium (RPC) funded by UKAID.

## 1.7. Outline of the thesis

This sub section includes the outline of the upcoming chapters starting from the upcoming second chapter.

Second Chapter. Literature Review and Theoretical Framework:

This chapter reviews the existing literature on issues related to/with the topic/area of the study. The main areas explored were the diabetes care, factors affecting adherence, health care provider and health care system issues. This chapter also includes the literature and operationalization and adaptation of the theoretical model used for the current study.

Third Chapter. Methodology and Research Site

This chapter includes the various methods and materials used for data collection and analysis. The chapter discussed the sample of the study and various data collection techniques used during the fieldwork including participant observation, key informants, face to face survey, informal and in-depth interviews and data collection tools. The case study (of *Chak Mangla* water) is also briefly oriented. The chapter also includes data analysis techniques including transcription and coding.

The sub-chapter of Research Site includes the thick profile of the research area (i.e., *Chak 104 Shumali*) starting from a brief overview of the district, province and also the country. The locale was presented according to different settings (including physical, social, cultural, environmental, political dimensions etc.). This sub-chapter also includes the characteristics of the study population.

Fourth Chapter. Experience and perceptions till diagnosis:

This chapter starts the debate of the initial steps of the journey of type 2 diabetes. It also explains how the cause of diabetes was perceived along with other related dimensions of it including time and mode of onset, pathophysiology, and severity and reaching the health facility before diagnosis.

Fifth Chapter. Experience of adherence to follow up:

This chapter takes the journey of diabetic towards issues in achieving adherence to the scheduled follow up visits. This chapter focuses on how respondents looked for cure and maximum benefits by visiting, using and utilizing treatments for various reasons such as easy to comprehend, culturally endorsed, involves less opportunity cost, easy to routinize and financially less burdening. This chapter categorized different treatments used as support/supplement treatment (that does not directly challenges the adherence to the follow up) such as *Chak Mangla* water and home based remedies. The alternate treatment includes local traditional herbalist and spiritual treatment. The chapter also summarizes with certain socio-cultural factors influencing adherence to the clinical treatment (i.e., follow up).

Sixth Chapter. Experience of lifestyle change:

This chapter explores different dimensions and factors influencing the adherence to the required lifestyle change. The concept of diet, exercise and smoking are discussed in its local context. The chapter finds a general everyday meal and how it is influenced by position/status in the family. The domestic hierarchy also shapes the decision towards physical activity especially space and time for exercise. The chapter also analyzes the factors as influencers towards suggested lifestyle change.

Seventh Chapter. Other factors influencing adherence to the treatment:

This chapter analyzes the factors that cross cut the adherence to the treatment in general in relation to the specific factors discussed in previous chapters. The chapter discusses different factors that cross cut specific factors influencing/affecting adherence to the clinical treatment and lifestyle modification.

Eight Chapter. Discussion:

This chapter includes the discussion on crystallized themes that emerged as important social and cultural factors affecting/influencing adherence to the treatment (both clinical treatment and lifestyle change counseling). This chapter also discusses the patients' explanatory model that may be used in similar settings.



Ninth Chapter. Summary and Conclusion:

This chapter concludes the discussion and debates created in the previous chapters. It includes how and what national and provincial programmes may find and learn to further contextualize the intervention. This chapter also suggests what may be included in the process of intervention that may increase the adherence to the proposed treatment.

Annex:

The Annexure includes the Non-Communicable disease card (on which the patients got registered and documented on each visit to the Rural Health Center). It also includes the desk guide used by the doctors and counseling tools used by the paramedics.

## **1.8. Definition of key terms**

The key terms are conceptualized and defined in the intervention car package section.

The operational definition of the key terms are as followed:

**Care Package:** The diabetes care package includes the desk guide, lifestyle counseling tool and smoking cessation tool.

**Treatment:** The treatment is majorly bisected in two sections i.e., clinical treatment and lifestyle modification counseling.

**Clinical treatment:** It includes diagnosis, prescription, drugs and follow-up

**Lifestyle modification:** It includes three major areas i.e., diet, exercise and smoking.

**Adherence:** At least four follow up visits (excluding the registration), out of the required eight visits were considered as adherent to the treatment.

NCD card, Desk Guide, Lifestyle and Smoking cessation tools are attached as Annex.

## 2. LITERATURE REVIEW

The medical anthropology has a peculiar interest in type 2 diabetes. The most significant reason resides in the alarming rise in the prevalence of the disease and the lack of effective methods to secure adherence to prescribed treatment(s). The disease hasn't yet resulted in any proven cures, however treatment(s) at best are able to manage the effects on a person's health and life-style. The current chapter documents the general landscape of the disease and its health outcomes, utilizes various models to explain adherence, explores the range of barriers that cause non-adherence, draws on the existing remedies and treatments in literature and looks at the various complications and co-morbidities associated with diabetes. The chapter also analyses the connections between adherence and age, gender, race, ethnicity as well as socio-economic factors.

Type 2 diabetes is characterized by inability of insulin to influence glucose and amino acid transport across the cell membrane (Manderson & Naemiratch, 2006). The disease affects individuals and communities on various levels, resulting in substantial direct and indirect complications and costs affecting communities and national economies (WHO, 1999). There has been a significant surge in the number of cases reported for diabetes mellitus, where 90-95% those reported are diagnosed as Type 2 (Hilalai, Mahdavi, Mobasseri, Jafarabadi, & Avval, 2016). Type 2 diabetes is affecting more than 285 million world-wide in developing and developed countries alike (Jiang, Lu, & Li, 2012). The escalated prevalence has been attributed to global economic shifts, increased urbanization and the associated lifestyle changes that has accompanied those (Sismanidis, et al., 2005). Additionally, income instability, food unavailability and affordability, everyday stress and anxiety, sedentary lifestyles and obesity are also factors that contribute to the high prevalence rate (King, Aubert, & Herman, 1998). It is estimated that global prevalence of the disease was 4% in 1995 and 4.2% in 2000. It is predicted that prevalence might grow as far as up to 5.4% in 2025 (King, Aubert, & Herman, 1998) (Wild, 2004).

Patient's own motivation and involvement towards the prescribed self-care regime stands as the most crucial aspect of diabetes management (Hilalai, Mahdavi, Mobasseri,

Jafarabadi, & Avval, 2016). The prescribed dietary modifications, regularity in exercise and movement and intake of medicines, are key to healthy living with diabetes (Jordan & Jordan, 2010). Despite the heavy role such life-style adjustments play in controlling the impact of the disease, these remain the most difficult and stubborn aspects, largely resisting any intervention or change required (Chechlac, et al., 2009) Non-adherence remains high in both developed and developing countries throughout the world (Garay-Sevilla, Malacara, Gonzales-Parada, & Jordan-Gines, 1998) (Khattab, Khader , Al-Khawaldeh , & Ajlouni, 2010). For instance, a study conducted in New Zealand revealed that only 22% of patients with type 2 diabetes reported complete adherence to the prescribed dietary modifications (Broadbent, Donkin, & Stroh, 2011). According to the US-based National Health and Nutrition Examination Survey [NHANES], 65, 28 and 18% of subjects with diabetes followed the recommendations for protein, saturated fat and fiber intake, respectively (Resnick, Foster, Bardsley, & Ratner, 2006). Lifestyle changes are known to produce desirable outcomes in diabetes management but remain the most challenging and adherence levels diminish over-time because of patient's clinging on to long-standing habits (Yoo, Lee, Lee, & Kim, 2007).

## **2.1. Diabetes care**

Diabetes care broadly range from introducing life-style changes, dietary recommendations and medication based regimes. Healthcare professionals ask patients with diabetes to carry out many self-care behaviors. These include dietary change, exercise, regular self-medication, insulin injection, self-monitoring of blood glucose (SMBG), insulin dose adjustment, and regular attendance (as scheduled) at respective health facilities and for screening programs amongst others.

Many researchers have conducted studies on lifestyle interventions and diabetes control, and have accumulated evidence confirming that in people with a high risk for the disease, type 2 diabetes can be prevented or delayed. A study conducted by (Knowler, et al., 2002) confirmed that the occurrence of type 2 diabetes was significantly lowered (by 58%) through lifestyle alteration and only 31% with metformin when compared with placebo. The effects appeared to be similar across both genders and along all racial and

ethnic groups. The efficacy of lifestyle intervention was same for young patients and old. The study demonstrated that within the ethnic and cultural groups in the US, intensive lifestyle intervention can be used to lower the prevalence of diabetes. The reduction of prevalence was the same in an identical study conducted in Finland (J, J, & Eriksson, 2001) and proved to be more significant than diet (31%), exercise (46%) and diet plus exercise (42%) in a study conducted in China (Pan, Li, & Hu, 1997). The lifestyle intervention introduced by authors was systematic, and intensive where the patients had access to the details of the intervention, the expectations they must have regarding results, and how to integrate it in their lives. However, the research was not intended to assess the compounding contributions of dietary changes, altered lifestyle, increased physical activity, and weightless towards the reduction of disease prevalence (WC, KMV, & RL, 1995). The findings of this study provided sufficient data and evidence regarding the efficacy of lifestyle intervention and metformin introduction in delaying or preventing the onset of type 2 diabetes in high risk communities. The lifestyle intervention was greatly resourceful, with a ratio of one diabetes case prevented per seven persons treated for three years.

## **2.2. Factors affecting adherence**

A study by Nam and Chesla identified 1454 articles published between 1990 and 2009 analyzing barriers to adherence in type 2 diabetes from PubMed, CINAHL, ERIC, and PsycINFO. The search looked through patient's barriers, clinician's barriers, and self-management (Nam, Chesla, Stotts, Kroon, & Janson, 2011). A common theme that arose confirmed that patient's knowledge, beliefs and attitudes affect self-care and management of diabetes. Moreover, culture and language also play an important role in determining patient's attitudes, beliefs and health literacy. Additionally, patient's financial resources, social support also play an important role. Diabetes management also significantly influenced by clinician's attitudes beliefs and knowledge. Practitioner's communications skills, and a well-integrated health care system contribute towards effective health management. Identifying barriers is key to understanding adherence and its lack.

There are various patient specific factors that influence adherence; beliefs, perceptions and attitudes, knowledge, financial resources, co-morbidities, ethnicity, culture and religion and language and social support.

Nam and Chesla found that active patient self-management is able to reduce healthcare costs, reduce risk of mortality and disability as well as improve quality of life (Gallagher, Viscoli, & Horwitz, 1993) (Horwitz & Horwitz, 1993) (Horwitz.RI, et al., 1990). Improved adherence to treatment regime helps ensure glycemic control and insulin levels. Failure to pay regular visits to clinician or keep appointments negatively impacts patient health (Nicolucci, Carinci, & Ciampi, 1998). Various studies have tried to look at how treatment adherence works across patients. It was found that single daily dose regimes had higher adherence than twice daily dose (Dezii, Kawabata, & Tran, 2002) Single medication or monotherapy regimens showed higher compliance than polytherapy regimens (Dailey, Kim, & Lian, 2001). Patients with diabetes had higher adherence to oral hypoglycemic intervention than insulin use (Rajagopalan, Joyce, Smith, Ollendorf, & Murray, 2003). Furthermore, diabetic patients perceived severity of disease and lack of understanding of health threats directly translates towards low adherence. Additionally, it was observed that the discrepancy in the perceived understanding of the disease amongst patient and practitioner also yields poorer results (Lawton, Peel, Parry, Araoz, & Douglas, 2005).

### **2.2.1. Patients' perception towards diabetes treatment**

There is a wide range of beliefs and attitudes that patients with diabetes hold, something which holds great significance for the treatment and care their condition receives, either from themselves or a practitioner. Patients also hold a range of beliefs and attitude towards treatments and medications which determines their perception about the need for self-care as well as self-care education and interventions. A total of 1202 diabetic patients were surveyed by Anderson et al using the updated version of Diabetes Attitude Scale (DAS) (Anderson, Donnelly, & Dedrick, 1990). The results confirmed a strong correlation between adherence outcomes and patients positive attitudes. Farmer et al. conducted a study on similar pattern and found similar results (Farmer, Kinmonth, &

Sutton, 2007). Patients' perceptions about treatment efficacy showed a strong correlation with patient's intention to take regular medication. Various other studies confirmed that patient's positive attitude towards diabetes management ensured better adherence towards lifestyle changes to control blood glucose levels than those with negative attitudes. (de Weerd, Visser, Kok, & van der Veen, 1990) (Dunn, 1990) (Masaki, Okada, & Ota, Importance of attitude evaluation in diabetes patient education., 1990).

The fact that type 2 diabetes has a natural progression suggests that 60% of patients with the problem will eventually need insulin treatment to optimally control blood glucose levels (Masaki, Okada, & Ota, 2002). Despite the proved effectiveness of insulin injections in controlling glycemic control in individuals with type 2 diabetes, various patients that would benefit from insulin therapy are not able to receive it, or do not receive it promptly enough (Davidson, 2005). In a recent research of insulin dependent patients with type 2 diabetes, nearly 33% reported reluctance towards insulin use if it was prescribed (Polonsky, Fisher, Dowe, & Edelman, 2003) (Larkin, et al., 2008). The avoidance and delays in initiating insulin therapy at the right time is governed by a variety of factors, primarily patients' attitudes and beliefs regarding diabetes and treatment (Hunt, Valenzuela, & Pugh, 1997) (Zambanini, Newson, Maisey, & Feher, 1999). Various patients perceive insulin therapy as something resulting from a personal defeat and consider it a punishment that is well deserved due to a failure to keep a healthy lifestyle (Davis & Renda, 2006). Additionally, patients suffer from injections phobia and are unlikely to do it daily based on the fear. Many other negative attitudes pertain to the idea that taking insulin results in limited or restricted lifestyle, and that insulin injection won't help alleviate the problem, and will in fact worsen situation and increase complications. Patients tend to avoid participating in self-care management owing to common misconceptions about the need for transitioning to insulin therapy

### **2.2.2. Awareness**

The relationship between awareness or knowledge and health outcomes has been inconsistent in literature. Knowledge has not proved to always lead to risk-reducing mechanism on patient's part. Individuals keep their habits and fail to comply despite their

best of knowledge regarding the gravity of risks (Avis, McKinlay, & Smith, 1990). A study focused on how does knowledge regarding a person's HbA1c (glycated hemoglobin) affects adherence and self-care understanding (Heisler, Piette, Spencer, Kieffer, & Vijan, 2005). Patients who had knowledge of their HbA1c values displayed better understanding of diabetes self-management and assessed their glycemic control more accurately as compared to respondents who did not know their HbA1c values. At the same time, it was observed that knowing one's HbA1c level alone was not enough for better understanding of self-management to influence the confidence and motivation necessary to influence actual self-care behavior. A study of about 670 adults cumulatively confirm the finding that better knowledgeable patients display a correlation with better diabetes management. Still, the patients were not able to reach metabolic outcome goals, nor did they receive the recommended ambulatory care for individuals with diabetes (Persell, et al., 2004).

Likewise, a study of 284 insulin-treated veterans with stable type 2 diabetes observed that patients with higher knowledge levels also had fewer perceived barriers to blood glucose monitoring ( $r = 0.211$ ;  $p = 0.006$ ). However, performance on the diabetes knowledge test was not related adherence to self-care, diet, exercise or medication. A multivariate analysis discovered that age, years of education, duration of disease and treatment, cognitive function, gender and depression levels independently determine the knowledge score (Murata, et al., 2003). Investigators in another study found that knowledge scores regarding diabetes and its symptoms and causes directly correlated with the prevention of diabetes-related complications (Pace, Ochoa-Vigo, Caliri, & Fernandes, 2006).

However, in a sharp contrast, Anderson et al. showed that low levels of knowledge about diabetes care and prevention correlated with a lesser likelihood of people developing strong attitudes about self-care, either positive or negative. Therefore, the existence of knowledge is not a firm or consistent predictor of compliance behavior, nor is it enough as a motivating factor to result in action. For instance, various individuals while complying to the recommended self-care routines expressed how they did not understand why they were doing a specific self-care and what the possible benefits were (Holmstrom

& Rosenqvist, 2005). Hence, there existed misunderstandings on various levels amongst patients despite regular check-ups and a decent level of access to health care facilities.

### **2.2.3. Culture/Ethnicity/Language**

Culture has a strong potential to influence a person's belief systems, understanding of disease and treatment aspects and even forms and levels of knowledge. Culture also is powerful enough to determine an individual's choices, attitudes, behaviors and habits and it is simple to see how cultural forces can interact with diabetic self-management and behaviors, and in turn, can affect diabetes self-management (Friedman, 1990). Fitzgerald et al. studied patients' expressed behaviors and attitudes (n = 672) toward diabetes by treatment type (insulin vs. no insulin), race/ethnicity, and the interaction of these two variables for Caucasians and African Americans with type 2 diabetes (Fitzgerald, et al., 2000). He found that Caucasians who were not employing insulin strongly expressed positive attitude and the least negative attitude toward diabetes care. The opposite was true for Caucasians who were using insulin: the latter group reported the least positive attitudes and the most negative attitudes toward diabetes care. Conversely, the African Americans group had lesser differences in the scores for the attitude scales between insulin users and non-users. An interesting finding outlined how African Americans reported a strong family support system and had favorable support from friends, in comparison with the Caucasians. Moreover, the encouragement African Americans received was interpreted by them more positively. Another study by Lipton and colleagues found that beliefs regarding adverse effects and insulin-related complications was profuse amongst Mexican American thereby resulting in non-compliance towards insulin therapy (Lipton, Losey, Giachello, Mendez, & Girotti, 1998). The same study observed that amongst Latinos, and even amongst low-income groups in urban residents, financial constraints are not as much of a barrier to adherence as emotional and cultural beliefs. The researchers concurred that since within Latinos cultural set-up, family needs are prioritized over all other expenditures, complying towards a medication regimen was perceived as selfish and self-indulgent, giving rise to guilt.



Culture related factors in diabetes management influence food choices and preferences, habits and lifestyle, and traditional beliefs about health and illness, e.g., Chinese value of enjoying food weighs heavily in the overall quality of life (Yao, Chung, Yu, & Wang, 2002). Taiwanese individuals with type 2 diabetes were studied in-depth by Lai et al. to understand their perspectives about their illness and treatment strategies (Lai, Lew-Ting, & Chie, 2005). The strategies included dietary restrictions and physical activities to increase mobility. Various participants thought that spa bath related sweating would decrease drug absorption and counter the toxicity of hypoglycemic agents. Up until now, none of the research on type 2 diabetes has focused on a systematic comparison amongst different racial and ethnic groups. A systematic study on Hispanics and their cultural patterns with regards to diabetes was conducted by Caban and colleagues (Caban & Walker, 2006). The review revealed that cultural factors that influenced diabetic self-care ranged from views about God, perceived cause of diabetes, use of folk healers, role of alternative treatments and fatalism differed by sub-groups within the Hispanics in United States and also by the level of individual acculturation. Caban et al. state that it is vital for researchers and health care provider to investigate cultural factors across the different sub groups. Moreover, it is important to note that a comment about Hispanics pertaining to the cultural determinants with regards to diabetes self-care will not be reflective of all Hispanics, therefore a context sensitive study which investigates individual sub-groups is important to make any claims.

A study by Polzer et al. notes that spirituality appears to be a central feature of African American culture and is deeply intertwined in their belief system and social fabric. It also mediates all aspects of life and shapes their views about illnesses, lifestyles, treatments and general longevity (Polzer & Miles, 2005). The researchers notes that spirituality potentially enhances the levels of motivation towards compliance behavior and results in greater likelihood of adherence, as seen in other illnesses e.g., cancer, HIV. Spirituality acts a source of God's support and grants legitimacy to self-care habits and self-management of illnesses (Polzer & Miles, 2005).

Language and communication affects patient practitioner relationship and thereby is known to enhance adherence. It is logical to see then, that language and communication barriers can also block or impede patient's understanding of disease, its risk and criticality of self-care. Lack of English proficiency is the main source of adherence-barrier faced by ethnic minorities in the US, and makes it difficult for them to communicate with the mainstream health care system and facilities. Particularly, the Hispanic community faces the largest set-back in health care facilities due to this communication gap and literacy barriers (Dagogo-Jack, Funnell, & Davidson, 2006). Lasater et al. designed a retrospective cohort study where 183 Hispanic patients with type 2 diabetes were Spanish speaking and control patients were English-speaking or bilingual (Lasater, Davidson, Steiner, & Mehler, 2001). The study revealed that the Spanish speaking patients were less likely to understand their prescriptions; 22% of Spanish speaking patients reported no comprehension vs. 3% of English speaking patients. A trend was also noted that the English speaking patients reported higher levels of compliance towards insulin-therapy than Spanish speaking cohorts. These findings suggest that language discordance between clinicians and patients has the potential to influence the process of patient education and awareness and thus negatively affects glycemic control in Hispanic patients with type 2 diabetes.

#### **2.2.4. Financial resources**

Financial constraint presents itself as a very serious problem and a potent barrier against diabetes management and self-care and affects across all cultures, particularly within groups which fall in lower social-economic strata or those which have little or no health insurance. A diabetes screening program in New Mexico revealed that lower level incomes and absence of health insurance were seen as primary reasons why patients (n = 118) with newly diagnosed type 2 diabetes did not seek and obtain medical care (Burge, Lucero, Rassam, & Shade, 2000). The correlation was strong as over 60% of patients with no health plan or insurance failed to obtain care after diagnosis compared with 6% of those who had insurance.

Furthermore, a 7 year study of Mexican Americans with type 2 diabetes (n = 908) showed that deficiency of health insurance was strongly associated with incoherent use of medications, something which produced the risk of kidney problems. (p = 0.008), all-cause mortality (p = 0.003) and diabetes associated death (p = 0.002) (Kuo, et al., 2003). Another study also demonstrated that a significant majority of people were prepared to cut their pills in half and skip doses to reduce cost owing to inability to afford recommended doses (Jerant, von Friederichs-Fitzwater, & Moore, 2005). Various other patients reported missing medical appointments because of lack of transportation and deficiency of funds required to take the bus or a cab.

### **2.2.5. Co-morbidities**

Competing co-morbidities, such as congestive heart failure, chronic fatigue, back pain, asthma, arthritis, depression and chronic obstructive pulmonary disease face barriers to diabetic self-management because of the complex demands of their over-lapping multiple conditions (Bayliss, Steiner, Fernald, Crane, & Main, 2003) (Bayliss, Ellis, & Steiner, 2007). A study claims that around 33% of people with diabetes suffer from an episode of major depression in their lifetime (Lustman, Clouse, & Freedland, 1998).

Another research focused on senior citizens with multiple comorbidities and their combined impact on patients' lack of physical activity, something which directly leads to lower likelihood of diabetes self-care and repetitive episodes of depression (Bayliss, Steiner, Fernald, Crane, & Main, 2003). It was noted that patients' with diabetes had twice the likelihood of developing depression than people without a chronic disease (Anderson, Freedland, Clouse, & Lustman, 2001) (Peyrot & Rubin, Levels and risks of depression and anxiety symptomatology among diabetic adults., 1997). What adds to this problem is the fact that a large number of patients with type 2 diabetes do not seek professional help for depression (Jerant, von Friederichs-Fitzwater, & Moore, 2005). Depression influences diabetes self-management and glycemic control as it has the power to alter the perception and beliefs regarding self-management of the disease and is connected with increased morbidity, mortality, functional limitation, and health care costs

(Lustman, Anderson, Freedland, de Groot, & Carney, 2000) (Chao, Nau, Aikens, & Taylor, 2005).

### **2.2.6. Social support**

A large number of studies demonstrate that absence of social support has the potential to shape perceived barriers to self-management and future mortality and morbidity (Cohen S. , 2004). It is noted however, that the significance of social support in diabetes care has resulted in mixed findings (Wing, Marcus, Epstein, & Jaward, 1991) (Gleeson-Kreig, Bernal, & Woolley, 2002). Wing et al. designed a research to analyze a family-oriented strategy for obese patients with type 2 diabetes (Wing, Marcus, Epstein, & Jaward, 1991). The findings demonstrated a gender divide in efficacy, where spousal participation in weight-loss education had a negative impact on men, leading to low adherence, while females showed positive response and demonstrated substantial weight loss with spousal support.

A cross-sectional study by Gleeson-Kreig et al. displayed that social support was not strongly linked to diabetes self-management for Hispanic participants who had large family networks and support systems (Gleeson-Kreig, Bernal, & Woolley, 2002). Therefore, differences across gender and race with regards to social support should be studied along with other contextual factors (e.g. socio-demographic factors). Furthermore, the researchers emphasized that health care models need to develop alternative support systems for patients without families.

### **2.2.7. Diet**

Despite the criticality of modified diet in type 2 diabetes management, all around the world, the frequency of adherence to dietary recommendations remains unsatisfactory among patients with diabetes (Garay-Sevilla, Malacara, Gonzales-Parada, & Jordan-Gines, 1998) (Khattab, Khader , Al-Khawaldeh , & Ajlouni, 2010). Faranak Hilali and Reza Mahdavi note that the phenomena of adherence to medical recommendations, dietary changes and lifestyle adaptations has been studied with regards to various variables in different societies (Hilalai, Mahdavi, Mobasseri, Jafarabadi, & Avval, 2016).

However, since every society is unique in its lifestyle patterns and eating habits and has a distinctive set of characteristics that dictate its social cultural religious and political structure, each society needs to be studied differently to see the range of the cumulative causations. Ma et al. conducted a study in 2003 which reported that 72% of adults had four or more eating episodes per day (Ma, et al., 2003). However, Iranian people had a 3 times a day eating routine. The same study also noted that only a 30% of those meals were consumed away from home. Additionally Iranians preferred home-cooked traditional meals. Their study looked at the specific reasons and factors that influenced adherence to dietary recommendations in developing country of Iran (Hilalai, Mahdavi, Mobasseri, Jafarabadi, & Avval, 2016).

#### **2.2.7.1. Situational barriers**

The difficulty in resisting temptations remains the most common problem of all diabetic patients all around the world. A large number of patients from similar studies on diet and lifestyle with regards to type 2 diabetes frequently mentioned how the lifestyle intervention and dietary modifications fall prey to various situational barriers particularly like special occasions, weekends, holidays, parties, gatherings and going on trips where the situation stand in between the patient and his recommended dietary plan for optimal control (Schlundt D. G., Rea, Kline, & Pichert, 1994) (Serour, Alqhenaei, Al-Saqabi, Mustafa, & Ben-Nakhi, 2007) (Vijan S, 2005)

Meal planning can be a great source of dietary compliance for diabetic patients, explain the researchers. Findings from Marcy, Britton, and Harrison (2011) also suggest how patients see inability to resist eating as the major source of loss of control over dietary compliance (Marcy, Britton, & Harrison , 2011). The tendency of diabetic patients to indulge in reckless eating habits, or consume unhealthy foods in certain situations presents itself as a major challenge regarding compliance for both patient and care provider (Chineye, Unachukwu, & Hart, 2007).

Research suggests that the conscious use of certain cognitive reappraisal strategies, like being mindful of the long-term benefits of avoiding the unhealthy food, and consciously

undermining or downplaying the effects of undesirable eating impulses can help ensure correct eating behaviour and allow for a better compliance and weight control (Giuliani, Calcott, & Berkman, 2013).

#### **2.2.7.2. Stress-related eating**

Inflation rates, high living costs, Negative attitudes, burn out, depression, anxiety, stress, and a host of other psychosocial problems are fairly common amongst patients with diabetes and has these issues have great significance on their regimen adherence (Black, Markides, & Ray, 2003) (Grant, Devita, Singer, & Meigs, 2003) (Lustman, Anderson, Freedland, de Groot, & Carney, 2000) (Peyrot M. , et al., 2005). It is important to emphasize that if the health professional assess the patient's eating habits as resulting from a psychological disorder or malfunctioning, the expert must look into the underlying causes that are promoting that behavior. The researchers of this study also note that there has been an overall rise in the expensiveness of clean or healthy diets, something which adds anxiety to the patients, particularly those from low socioeconomic backgrounds.

Therefore, future studies should look at the relationship between the so called 'expensive diet' on patient's stress levels. Patients must be guided towards dealing with the rising costs, and educated about cheaper healthy alternatives, how to cook a healthy meal at home and more awareness regarding clean eating habits that do not present themselves as an expense, something which may promise a better dietary adherence.

#### **2.2.7.3. Difficulty with meal plans**

A study on diet and diabetes conducted by Connell (1991), showed that only 69% of diabetic patients adhered to their recommended meal and snack schedule (Connell, 1991). A 62% of participants in Iran's study (Hilalai, Mahdavi, Mobasseri, Jafarabadi, & Avval, 2016) reported that they found timing or scheduling their meals or counting the meals consumed as a barrier and found it difficult to adhere to. It was also seen that obese women had irregular meal patterns (Bertéus, Lindroos, Sjöström, & Lissner, 2002).

Participants with diabetes often report taking irregular meals. Research suggests that insulin sensitivity is affected by frequency of taking irregular meals, something which holds true for even non-diabetic people (Farshchi, Taylor, & Macdonald, 2004). Better blood glucose levels are possible with having more regularity in meals (Øverby, Margeirsdottir, Brunborg, Andersen, & Dahl-Jørgensen, 2007). Hence, it appears that the total calorie intake daily through with a help of scheduled meal timings and regular meal planning is healthy for both, diabetic and non-diabetic people (Chineye, Unachukwu, & Hart, 2007). Since most of the diabetic patients struggle with weight, proper dietary routines, complemented with other behavioral changes, can help them improve glycemic levels and also help target their weight (Talbot & Avery, 2001).

#### **2.2.7.4. Confusion about the dietary recommendation**

Patients with diabetes have reported confusion has been reported as one of the major barriers to dietary adherence (Vijan, et al., 2005). A study conducted by Hilalai and Mahadavi (2016) explains how majority of patients reported how they were unsure about how much and what they were required to eat which could complement their condition. (Hilalai, Mahdavi, Mobasseri, Jafarabadi, & Avval, 2016)

They also exhibited poor knowledge regarding which foods belonged to what food category. This was reported despite the fact that dietary instruction were given to them in print. It is important that health providers take into account the ease, flexibility and understanding of the patient and try to simplify the diet patterns and instructions as much as possible.

#### **2.2.7.5. Work-related problems**

There have been studies conducted in the past which noted how irregularity on work, or uncertain work hours also affected diet heavily and interfered with patient's adherence to dietary recommendations (López-Azpiazu, Martínez-González, Kearney, Gibney, & Martínez, 1999) (Kearney & McElhone, 1999). For instance, having a tea break in offices or not having one, both affects patients in their own way.

In Iran, the researchers noted that it was not customary to have a tea break in office or other work organizations. For patients with diabetes, the research suggested that having tea breaks was more beneficial than not having one because it adds an element of planned meal in the equation.

#### **2.2.7.6. Small portion sizes**

Amongst patients with obesity, creating small weight reduction goals, like reducing a portion size resulted in better glycemic control and blood glucose level (Talbot & Avery, 2001). Research suggests that health care and wellness professionals should ensure that dietary recommendation should comply with the weight demands of the patients. For instance, in a study conducted by Hilalai and Mahadavi (2016) it was observed that various patients felt torn between the need to eat the prescribed meal and feeling hungry and low on energy (Hilalai, Mahdavi, Mobasseri, Jafarabadi, & Avval, 2016).

Many reported how the amount of food recommended was not enough to help feed their hunger. Various other studies on portion control had similar results that small portion sizes led to hunger. (Vijan, et al., 2005) (López-Azpiazu, Martínez-González, Kearney, Gibney, & Martínez, 1999). The researchers suggest that if a diet plan takes into account the amount of food and is coupled with advice on how to reduce hunger at the same time can be of great help for patients regarding adherence.

#### **2.2.7.7. Lack of family support**

Monotonous diets for patients is a challenge that not only patients face due to getting bored but also for their families as special preparation is required. Research suggests that having to follow a monotonous diet induced feeling of deprivation (Kapur, et al., 2008) (Marcy, Britton, & Harrison, 2011). Once a patient feels driven to eat out of deprivation, it leads to subsequent weight gain followed by spontaneous eating episodes (Yannakoulia, 2006). Patients often report lack of family support in sticking to recommended diet. (Schlundt D. G., Rea, Kline, & Pichert, 1994) (Vijan, et al., 2005) (Ziebland, Thorogood, Yudkin, Jones, & Coulter, 1998). Patients who reported 'lack of family support' also noted that they 'do not like foods in diet' and they cited a



'monotonous and boring diet' as barriers to dietary adherence. Hence, research suggests that the recommended diet by health expert should keep in mind the general family diet and shows them ways about how to achieve this.

To address these persistent issues regarding adherence to diet, a comprehensive diabetes education and management programs need to be designed with pronounced focus on individual barriers. Generally, chronic conditions require a long-term approach of lifestyle modification and special dietary regimens. In order to ring about a change in long-standing habits and behaviors, it is critical to alter the person's underlying beliefs and attitudes related to that behavior (Bundy, 2004). Cognitive behavioral techniques are repetitively stressed by research, in order to achieve better results in adherence. For instance, Motivational Interviewing (MI) is one such technique, something which has a patient-centered approach.

MI targets a person's need, desire, ability and motivation to create a change (Hetteema, Steele, & Miller, 2005). MI can be of great use by health professionals to identify patient's individual perceptions about their situations and their beliefs about recommended diets for diabetes management and also to eliminate resistant barriers. Globalization has resulted in dietary patterns which are largely universal despite nuanced cultural influences through urbanization and population growth. For instance, researchers working in Iran did not find drastic variance in eating patterns. Their findings suggested that there existed no drastic differences in barriers that patients with diabetes faced. Instead, the issues they saw with patients in Iran were very closely identical to the ones seen in developed countries like USA, Germany etc. (Ghassemi, Harrison, & Mohammad, 2002).

Studies of dietary patterns are important and contribute greatly towards factors that influence prevalence as well as management of diabetes. In the context of Iran, two dietary studies have been conducted which identified western dietary patterns (high in refined grains, red meat, butter, processed meat, high-fat dairy products, sweets and desserts, pizza, potatoes, eggs, hydrogenated fats and soft drinks yet, low in other vegetables and low-fat dairy products) as existing predominantly in the developing

country of Iran (Esmailzadeh & Azadbakht, 2008) (Rezazadeh, Rashidkhani, & Omidvar, 2010). Nutrition is highly dependent upon economic shifts and demographic changes. Food patterns are closely shaped by household incomes. Government involvement in form of subsidies also determine dietary patterns (Ghassemi, Harrison, & Mohammad, 2002). Studies regarding dietary adherence in type 2 diabetes should use an exploratory factor analysis method. However, it must be noted that self-reported data is always subjected to an inherent bias. Studies should also take into account differences in gender when looking at dietary patterns of persons with diabetes.

### **2.3. Gender**

There is overwhelming evidence of the fact that around 80% of type 2 diabetes cases are preventable through healthy nutrition and regular exercise (World Health Organization, 2009). The risk factors are modifiable and interventions that target to modify them can actually reduce the occurrence of the condition. (Lindström, et al., 2003) (The Diabetes Prevention Program Research Group, 2002) (Tuomilehto, et al., 2001). By increasing the physical activity and improving mobility, by reducing blood glucose levels and body mass index, women have shown great reception to it. (Gilis-Januszewska, et al., 2001) (Walker, Piers, Putt, Jones, & O’Dea, 1999) (Whittemore, Melkus, & Grey, 2005). While the studies cited provide evidence that lifestyle interventions can reduce risk factors for type 2 diabetes in women, there is evidence that many people have difficulty modifying their behaviour to reduce risk factors. For instance, the Diabetes Prevention Study evaluated the effects of a randomised controlled trial of a lifestyle intervention focusing on diet and physical activity in middle aged men (n = 172) and women (n = 350) with a weak glucose tolerance (Lindström, et al., 2006). A study found that the relative risk of diabetes was reduced significantly. However, at a follow-up of the study a year later, it was observed that one-third of the participants matched none of just one of required goals of weight loss, dietary and physical activity study goals and described that adherence to the prescribed intervention was difficult and challenging. The reasons for non-adherence are multi-factorial and has various socio-cognitive causative factors that affect healthy eating habits and regular exercise.

A study by McGuire, Anderson, & Paul, 2014 explored the level and type of perceived barriers to health promotion in midlife and older women with type 2 diabetes (McGuire, Anderson, & Paul, 2014). When compared to other studies using the BHADP to measure the barriers, the average score in this study (32.12) is similar. For example, Stuifbergen and Becker (1994) found that adults with a range of disabilities had an average barriers score of 33.5; adults with multiple sclerosis had an average score of 32.54, while adults with post-polio syndrome an average of 33.12 (Becker & Stuifbergen, 2004). A sample of 198 women with fibromyalgia was reported to have a higher average barriers score of 36.74 (Beal, Stuifbergen, & Brown, 2009). Interestingly, these scores are qualitatively much higher than those of adults without disabilities, whose average score reported by the scale authors was 25.07 (Becker, Stuifbergen, & Sands, Development of a scale to measure barriers to health promotion activities among persons with disabilities. , 1991). It was noted that participants in this study with type 2 diabetes had barrier level which was similar to adults with multiple sclerosis, a physical disability. Perhaps the results are consistent with estimates (AIHW, 2010) that a lot of older persons with diabetes do possess some disability or frailty. The authors analyzed the barriers individually in patients and they learnt that the most prominent barriers on the scale appeared to be the following: not interested; concern about safety; too tired; lack of money; feeling what I do doesn't help and; lack of time. The finding hold a lot of similarity with other studies about barriers in older diabetic women. There is also convincing evidence that safety concerns, fears of injury and falling are critical barriers that impact on older women's' levels of exercise and physical activity (Bird, et al., 2009) (Crane & McSweeney, 2003) (Lucas, Orshan, & Cook, 2000) (Newson & Kemps, 2007) (Jones & Nies, 1996). Older women have also reported lack of motivation and fatigue as barriers in a number of studies (Bird, et al., 2009) (Crane & McSweeney, 2003) (Lucas, Orshan, & Cook, 2000) (Newson & Kemps, 2007). The feelings of lacking-self-efficacy or a low confidence in the effectiveness of the actions of compliance also presents itself as a barrier that negatively implicates patients' perceptions and beliefs. The literature describes these as strong indication of perceived barriers. (Lucas, Orshan, & Cook, 2000) (Nies & Kershaw, 2002) (Shin, Hur, Pender, Jang, & Kim, 2006).

Contrary to the dominant barrier studies, the scarcity of time did not present itself as one of the most important barriers for the participants of this study of older women (McGuire, Anderson, & Paul, 2014) , however nearly half of them reported that it was an issue at times. For midlife and younger women, in contrast, lack of time was one of the most consistently reported barrier in health promotion and self-care, preventing them from exercising with regularity (Bowen, Balsam, Diergaard, Russo, & Escamilla, 2006) (Heesch, Brown, & Blanton, 2000) (Mosca, McGillen, & Rubenfire, 1998) (Osuji, Lovegreen, Elliott, & Brownson, 2006). The researchers comment how the findings are not strange given that women in mid-life or younger are often assumed to be responsible for juggling work and home and myriad of commitments that come along with it. Furthermore, in contrast to the majority of studies regarding women facing barriers in health promotion, (Ansari & Lovell, 2009) (Eyler, et al., 2002) (Juarbe, Turok, & Perez-Stable, 2002) (Wilcox, Bopp, Oberrecht, Kammermann, & McElmurray, 2003) the variable of ‘other responsibilities’ were one of the lower ranked barriers items, however almost half (46%) reported it was a barrier ‘sometimes’. The study by McGuire et al (2014) had participants which were older and retired from work, and in comparison against younger women, these were less likely to be implicated by primary care responsibilities for children and elderly parents (McGuire, Anderson, & Paul, 2014). It is also true that older women may also have responsibilities of their grandchildren. The researchers suggest conceptualizing the barriers by categorizing them into personal, social and environmental segments. It was found that personal barriers (e.g. ‘not interested’ and ‘feeling what I do doesn’t help’) were ranked as the highest and perhaps represented low motivation and lack of perceived self-esteem in the group. The study found that most women of 65 years in average were found to be overweight, had type 2 diabetes and had high levels of fatigue. The researchers hypothesized that these factors that were most probably the result of low levels of motivation and confidence and willingness to indulge in activities and healthy lifestyle. Moreover, these factors also contribute to, or are caused by depression and anxiety and various forms of mental illnesses.

However, the researchers did not measure these specific factors in this study, but they are more prevalent in people who are in poor physical health. (National Survey of Mental Health and Wellbeing: Summary of Results, 2007) There were a good number of patients who expressed how they felt embarrassed about their body and appearance to some degree. This issue of embarrassment was the most important factor that would have contributed to their unwillingness to work out in public resulting in them being overweight and possessing low self-esteem. Most women also mentioned social factors, including lack of money and support from family and friends. Again, this finding did not come as a surprise given the fact that most participants reported belonging to a low-income group and around half were single, widowed or divorced therefore, were likely to be living alone. There is also convincing scientific reasons that people over 65 years of age and who are living alone are more likely to have poor health, poor diet, functional impairment, low physical activity and a tremendous risk of falls (Kharicha, et al., 2007). These factors also have the strength to explain high average barriers score in this study.

Amongst older and middle aged women, researchers found that environmental factors for instance bad weather, lack of convenient facilities, problems with transportation were not the highest ranked barriers items, however these remain issues that do affect a proportion of participants (20-50%) sometimes or often. For example, in the study of Australian older and middle aged women, researchers saw that since Brisbane had a sub-tropical climate with high heat and humidity in the summer months, almost half of the women expressed how bad weather did pose as a significant barrier.

Moreover, exercise facilities such as gyms were possibly not attractive to older overweight women (Lee, 1993) and additionally are unaffordable to the women from low-income groups. 22% of participants in this study viewed transport issue as a complex barrier which put constraints on their mobility and agency to plan outdoor activities, go to parks for walks etc. Various participants also voiced concerns regarding falling and injury and the fear of walking alone. Hence, when older women are unable to join gym or fitness centers and are also uncomfortable in working out in public spaces, they might

even feel unsafe in talking a walk in the neighborhood, thereby narrowing the already limited choices for physical activity and exercise.

There is yet another set of barrier to health, which comes under lack of professional help and support where women responded how they faced difficulty in communicating their problems to their health provider and also are upset at the lack of information that results from poor communication. Nearly one-third of participants report that a professional's lack of support is sometimes a barrier and various others report that insufficient information about what and how to do something is also a barrier. One fifth of participants also report sometimes having difficulty with communication as a barrier. These results contain deep and long-running implications for clinical practice and provision of health service, especially since all the participants were taken from community health clinics and centers providing allied health and specialist diabetes nurse educator services.

## **2.4. Health care provider factors**

Nam and Chesla noted that a large majority of published literature related to diabetes self-management entirely frames its focus exclusively on patients, in effect down playing factors related to clinician and patient-provider interactive space. The researchers point out that patients and health care providers differ massively in their perceptions of disease and treatment, knowledge regarding risks, and attitudes towards treatment, something which results confusion and even conflict, thereby ensuring poor outcomes (Anderson, Fitzgerald, Gorenflo, & Oh, 1993).

It is then essential to note that to improve diabetes self-management and its quality, there exists a need to procure a reasoned and logical understanding of clinician factors. Clinician's barriers evaluated by researchers (Nam, Chesla, Stotts, Kroon, & Janson, 2011) and looked at belief, attitude, knowledge, communication, and health system.

### **2.4.1. Beliefs, attitudes, and knowledge**

Attitudes and behaviors displayed by physicians towards patients is much more critical than their knowledge or level of expertise in diabetes management. A research by Puder and Keller confirmed that clinician's attitudes, beliefs and knowledge has substantial influence on patient's compliance to recommended regimen. It was also noted that many clinicians did not view type 2 diabetes as a serious threatening condition (Puder & Keller, 2003). Dietrich saw that clinician's attitude while confirming the diagnosis was an important factor in determining patient's tendency to conform to prescribed regimen as well as self-management behavior (Dietrich, 1996). The researchers examined the behaviors expressed by patients at the time of diagnosis, which were ranging from fears, panicking, anxiety, shock and being resigned. Dietrich also noted that when the physician downplayed the gravity of the disease, it was taken as less serious by the patient. In the same vein, Hunt and colleagues noted that in addition to personal expectations and experiences, the attitudes and behaviors of clinician determined whether patients react positively or negatively to insulin therapy (Hunt, Valenzuela, & Pugh, 1997).

Larme et al. studied the behaviors of primary care providers toward diabetes (Larme & Pugh, 1998). Their findings suggested that majority of providers understood diabetes as much more complicated and harder to treat than hypertension. A majority also rated hyperlipidemia and arthritis as treatable and as easier to manage than diabetes, but the ratings were not statistically significant. Larme and associates also conducted qualitative analysis to develop an in-depth understanding of care-giving attitudes. The analysis highlighted that the health-care providers displayed unsure attitude regarding efficacy of diabetes treatment and also doubted their own abilities to provide it. This research finding highlights that clinician attitude towards perceived efficacy of treatment has consequence for actual diabetes management, particularly during the patient-provider interaction as both parties display tier frustration regarding the condition and its management. The patient potentially perceives this frustration, or inability of the doctor to take charge of the condition as a loss of control over effects of diabetes, something which has lasting consequences on the patient's empowerment in diabetes self-management. The clinician's lack of knowledge about recent evidence based guidelines may affect the diabetes care

outcome. In specific, diabetes care givers are unsure about when to start administering and are also uncertain about the quantities that should be given (Brown, et al., 2002).

It is also worth noting, that a majority clinicians are oblivious to the psychological needs of their patients (Peyrot M. , et al., 2005). A cross-sectional study conducted in over 13 countries of 3827 providers and 5104 adults with type 2 diabetes revealed that only 10% of patients reported that they received psychological treatment. This is alarming in the backdrop where 41% of patients with diabetes experience psychological symptoms which negatively affects their ability to self-manage their diabetes. Moreover, many clinicians reported how they doubted their ability to diagnose and provide adequate treatment and support to the psychological issues of their patients. The findings of such studies point to the dearth of understanding of the need to target attitudes and beliefs of health care providers and their ability to influence a collaborative self-care model in mutual participation with their patients. Health models should focus on altering the perceptions of the clinicians in order to have substantial gains in self-management of diabetes (Brown, et al., 2002) (Larme & Pugh, 1998). There is also the need to incorporate skill training in recognizing and managing psychological distress.

#### **2.4.2. Patient–provider interaction and communication**

The beliefs and perceptions of illness within patients is greatly determined by the nature of care they receive as well as the interaction they hold with their health care provider. The nature and communication efficacy is very critical aspect which has direct consequences for patient’s self-beliefs as well as resultant adherence (Lawton, Peel, Parry, Araoz, & Douglas, 2005). Positive patient– provider communication promises better diabetes self-management, better diabetes outcomes, or both (Schillinger, Bindman, Wang, Stewart, & Piette, 2004). However, many patients witness various barriers in collaborative diabetes management, which in turn affects adherence (Schillinger, Bindman, Wang, Stewart, & Piette, 2004).

It is also interesting to note that most clinicians realize that they lack effective communication tools and skills that could prove as positive counseling and enable shared



decision-making (Wens, Vermeire, Royen, Sabbe, & Denekens, 2005). The professionals themselves perceive this lack of skill to be a barrier for efficient diabetes treatment (Hunt, Valenzuela, & Pugh, 1997). A study designed in primary care setting observed 367 patients with types 1 and 2 diabetes and revealed that poor patient–provider communication was positively associated with poor treatment adherence (Ciechanowski, Katon, Russo, & Walker, 2001). A modest number of randomized controlled trials (RCTs) were conducted to see whether interventions which were clinician-focused were able to improved clinician–patient interaction and communication as well as patients’ diabetes outcomes (Kinmonth, Woodcock, Griffin, Spiegel, & MJ., 1998) (Pill, Stott, Rollnick, & Rees, 1998) (Woodcock, Kinmonth, Campbell, Griffin, & Spiegel, 1999). Unfortunately, it was found that while clinician-focused intervention did improve the patient-practitioner interaction, however the correlation was not significant. The interventions were still unable to influence levels of knowledge of patients, treatment adherence, HbA1c, Body mass index and other cardiovascular risks in patients (Kinmonth, Woodcock, Griffin, Spiegel, & MJ., 1998). Conversely, in the other RCTs that were set to test patient-focused interventions, improvements in patients’ psychosocial factors (i.e., diabetes knowledge, attitude and self-efficacy) as well as biomedical factors (i.e., HbA1c, BMI and cardiovascular risk factors) were observed (Anderson, et al., 1995) (Piette, Weinberger, & McPhee, 2000) (Trento, et al., 2001). Hence, it was concluded that to alter the attitudes of clinicians, even with the help of focused interventions was much more resistant It may be difficult for clinicians to change their communication style to one that is more effective, even when supported by special training programs.

Moreover, it is possible that clinicians don’t find it feasible to complement their daily practice with the most comprehensive style of diabetes self-management that caters to their psychological and social issues in addition to providing them with adequate biomedical and metabolic management and medication.

### **2.4.3. Health care system**

It was found that over 75% of individuals who are diagnosed with type 2 diabetes receive diabetes care exclusively from primary care providers (Shumaker, Schron, Ockene, &

McBee, 2004). It is alarming then note that only about one-third of those diagnosed are able to fully comply with the recommended care and treatment. Yet, only about one-third of patients with type 2 diabetes correctly follow the health care provider's directions for diabetes care. The current health care system is designed in manner where practitioners are overstretched and burdened, with the urgent need to complete various tasks, including provision of preventive activities, dealing with chief complaints and write prescriptions – all in a 10 to 15 minute visit. Therefore, it is problematic for primary care providers to allocate such large time brackets to the behavioral, psychosocial, and emotional issues of patients with type 2 diabetes. There is evidence which supports the idea that with longer appointment times for chronic diseases, provision of automated reminder systems, and tools such as flow sheets or checklists can improve diabetes care (Eytan & Goldberg, 2001).

Ziener and colleagues conducted a 3-year randomized controlled trials to see if having computerized alarms that provide performance improvement feedback and patient-specific recommendations at each visit results in providers' intensifying diabetes therapy appropriately and improve diabetes outcomes in a primary care setting (Ziener, et al., 2006). At the end of the research, Ziener et al. noted that receiving computerized reminders alone was unable to show any statistical difference in propensity to intensify treatment as compared to a control group of providers. Nonetheless, providers who received computerized alarms along with performance improvement feedback and providers who only received performance improvement feedback showed significant improvements in their efforts to intensify diabetes therapy compared to the control group providers, highlighting that feedback on performance improved provider behavior and lowered patient's HbA1c levels.

Another randomized controlled trials measured the effect of a multifarious intervention focused at general practitioners (GP) on mortality, morbidity, and risk factors of patients with newly diagnosed type 2 diabetes (Olivarius, Beck-Nielsen, Andreasen, Horder, & Pedersen, 2001). The multifaceted strategy provided to 484 general physicians included regular follow-up and individualized goals for diabetic persons supported by prompting

doctors, clinical guidelines, feedback, and continuing medical education and evaluation. Intervention physicians conducted more follow-up appointments and consultations and became more dedicated on lowering risk factors through setting goals. The results pointed out that in a primary care setting, individualized goals combined with a context of educational support for physicians reduces risks associated with diabetes-related complications in patients with type 2 diabetes.

## **2.5. Theoretical models and adherence to the treatment**

This section deliberates upon the existing psychological, social, cultural, behavioral, cognitive, and organizational models that explain compliance behavior, role of education, intentions and perception in behavior, as well as structural factors that influence adoption and implementation of diabetes management techniques.

Healthcare professionals require diabetic patients to carry out a number of self-care behaviors, ranging from dietary modification, routine exercise, insulin injection and monitoring of blood glucose levels (Lawson & Harvey, 2009). More often than not, these crucial behaviors on patient's part are not achieved, despite the fact that patients themselves sufficiently understand the importance of these. There has been an enormous emphasis on the importance of education, and it seems plausible to say that lack of awareness remains the most straightforward and easily addressable issue in patient self-care (Jordan & Jordan, 2010). The information delivery, target population, methods through which extra support is provided together aims to target the attitudes and beliefs of patients. However, Mazucca's findings from a meta-analysis of 30 studies highlighted that information alone is almost never sufficient or guarantor of adherence to self-care regimes (Mazucca, 1982). A review of around 20 studies confirmed absence of any direct link between education and adherence (Anon, 1992). Patients with great level of educations display low adherence (Scott, Al-Deagi, & McElnay, 1995). Hence, Lawson and Harvey suggest that we must move beyond education and knowledge.

The phenomenon of 'barriers' was initially explained by (Becker M. , 1974) in his health belief model, where he defined it as the obstacles or impediments that prevent the person

from taking action to minimize the threat of illness. Another variation of the health belief model by Pender further expands the definition of ‘barriers’ to include ‘perceptions concerning the unavailability, inconvenience, expense, difficulty, or time consuming nature of a particular action’ (Pender, 2006, p. 53). There is strong evidence from research based on the health belief and health promotion models, that the concept of perceived barriers is an important predictor of health promoting behavior (Glanz, Rimer, & Viswanath, 2008) (Janz & Becker, 1984) (Pender, 2006).

According to (Lawson & Harvey, 2009), Health Belief Model (HBM) has identified five basic categories that define behavior: how a patient perceives severity of the disease, how a patient views his own vulnerability to the issues of disease, how beneficial does the patient views treatment as, the perceived costs involved and cues to action (Becker M. , 1974) (Becker & Maiman, 1975), which can be internal or external. Harvey and Lawson mention two meta analyses published, one of which found perceived barriers to self-care as a strong influencer (Janz & Becker, 1984). It was noted that patient’s perception of severity of disease coupled with efficacy of treatment led to sick-role behaviors after diagnosis. Harrison et al however noted that despite identifying the principle contributors to self-care behaviors (i.e., perceived susceptibility, severity, barriers, benefits and cues to action) diabetes studies revealed inconsistent results (Harrison, Mullen, & Green, 1992).

It was observed that adherence in adolescence was influenced by perceived benefits (minus costs), whereas adults were more influenced by benefits and vulnerability (Brownlee-Duffeck, et al., 1987). It was also worth noting that an emotional equation might be influencing the behavior of outright denial that is perceived severity may have two opposing set of effects on different individuals, i.e., better adherence or denial. However, HBM does not incorporate emotional correlation in its analysis.

Theory of Reasoned Action (TRA) asserts that individual’s behavior is contingent upon intention which is determined by two main things; firstly the patient’s attitudes towards the behavior and the set of expectations he has regarding the efficacy of that behavior (Ajzen & Madden, 1986). Secondly the subjective norm, or the perceived social pressures

regarding performance of that behavior. The former maintains that if a person sufficiently believes in the positive outcome of a behavior, he or she is more likely to perform it. The latter assumes that if the person seeks approval of family, friends, significant others etc., he or she will be motivated to comply and work through the barriers to perform that behavior. Hence, TRA analysis patients within their subjective social and cultural contexts.

It is still critical to note that despite having motivation and solid intentions to perform a behavior, the desired result or action is not achieved. It is then important to take into account yet more factors. TRA has been studied and used to explain patient's compliance with regimen with variable success (Miller, Wikoff, & A, 1992) (Connor & Norman, 1996). With regards to diabetic patients, DeWeerd et al. found a correlation between intention and behavior, with some influence of social norm (DeWeerd, Visser, Kok, Van, & Veen, 1990).

Behavioral Psychologists and health professionals also employ Protection Motivation Theory to explain compliance behavior. PMT basically evolved from fear communication theories (Rogers R. , 1983) and these 'Fear Appeal' studies interest health care professionals who see value in communicating risk factors to patients and reiterate health protective behaviors. The Drive Model, which was an 'early fear' appeal model maintained that frequency or likelihood of protective behavior is directly proportional to the amount of drive or fear created. While the model realized that high levels of fear will be counter-productive, derailing or demoralizing the patient into altogether non-compliant behavior or outright denial, they still asserted that moderate levels of fear was beneficial for procuring protective behaviors with regards to health. The Drive model did not receive research findings that could legitimize its validity (Beck & Frankel, 1981).

Recently, much attention has been given to the beliefs and ideas that patients harbor reading illness. According to Leventhal, there is a two-way reaction on part of patients when confronted with fear of disease. They either respond to avoid danger or react to avoid the fear or emotion of feeling that danger. (Leventhal, Meyer, & Nerenz, The common sense representation of illness danger, 1980) (Leventhal, Diefenbach, &

Leventhal, 1992) (Leventhal H C. L., 1987). Leventhal purported a Self-regulatory model of Illness (SRM, also known as personal model of illness) which suggests that there are independent cognitive and emotional processes operating in a patient. One regulates danger, and the other regulates the fear of danger or emotionality of danger. These two are operating parallel with each other and are known as danger control and emotional control respectively (Weinman, 1987). Leventhal explains how illness cognitions are patient's own sense or beliefs regarding their illness.

The SRM asserts that the patient possesses agency and considers them as an active problem solver, thereby minimizing the perceived gap between his or her current state and the self-thought ideal state (Hampson, et al., 2001). Therefore, patients receive, understand and interpret the incoming information and use it to address their problem. SRM suggests there are three stages through which this behavior results; representation, coping, and appraisal. Representation refers to the stage when patient's cognition recognizes or detects a threat. Coping refers to the proposed action plan a patient considers adopting. Appraisal stage refers to that point where patient measures or analyses the progress achieved via action plan or coping, something which may lead to cues to modify representation or coping strategies. The model presents features of dynamic interaction between these three stages, the parallel processing of cognitive and emotional reasoning as well as the interaction between the two stated processes (Leventhal & Cameron, 1987).

Leventhal conducted various interviews with patients of chronic illnesses and studied the core characteristics of a patient's conceptualization of health threats (Leventhal H N. D., 1985), (Leventhal & Diefenbach, 1991). The representations he studied were patterned around four components: Identity, cause, course, and consequences. Identity referred to the beliefs about labels associated with the sickness. Cause refers to the various perceived reasons and beliefs for the disease acquisition, e.g., heredity, environmental variables, age, lifestyle. Time line or course pertains to the predicted duration of the disease e.g., acute, chronic, recurrent or cyclic. Finally, consequences refer to the beliefs held about the physical, social, psychological and financial cost or consequence of the illness. Lau

and Hartman added another pertinent dimension to this model: Curability or controllability; the extent to which the effects of the disease can be altered, reduced or controlled by treatment or individual (Lau & Hartman, 1983). An important core feature of this element is the belief about treatment efficacy or perceptions of self-control. Personal models with reference to various illnesses have been studied, and used to predict or explain health behaviors (Petrie & Weinman, 1997). Much more than perceived barriers, what determines compliance more accurately is perceived benefits or efficacy of the treatment (Glasgow, Hampson, Strycker, & L, 1997). These appear to be much more steady and consistent than measures related to depression (Hampson, Glasgow, & Strycker, 2000). The SRM model is unique and offers something different from previous models of health, in that it takes into account the patient's past as well as current experience. Various health professionals prefer this model as it gives agency to the patient and considers him as a thinking acting being who has the ability to take action and change or alter his health condition. This model also values the issues that patients themselves identify as important.

The personal model of illness identifies that there is an emotional response to illness on behalf of the patient. The SRM asserts that patient's perception can be influenced to develop a more positive and constructive approach and understanding towards illness, and later their belief about the efficacy of action or treatment. The SRM along with Personal Models of diabetes can be theoretically employed to analyze and predict the adherence or self-care behavior in diabetic patients.

Additionally (Lawson & Harvey, 2009), explain that illness representations of coping mechanisms are influenced by a range of external factors like social environment, media, family, as well as experiences with illness in the past. The coping responses are directly translated by the way a patient represents the threat or illness. Clinical outcomes are affected by the form of coping behaviors that can be categorized as adaptive (self-care) or maladaptive (avoidance or denial). Coping mechanisms can be broadly categorized as: avoidance/denial, cognitive reappraisal, expressing emotion, problem-focused coping or seeking social support. Avoidance/denial or expressing emotion (passive coping

mechanisms) are in reaction to the emotional identification of threat under SRM. Moreover, active problem-focused coping means that patient has positive reappraisal and belief in efficacy, will result in improved clinical outcome and most likely lead to compliance behavior, e.g., suboptimal glycemic control by utilizing the clinical advice given). Emotion-focused coping generally leads to unstable and unhealthy outcomes (Lawson, Lyne, Bundy, & Harvey, 2005). Passive coping in many illnesses has been associated with poor health outcomes and worse social and physical functioning, however active coping has yielded positive health benefits (Rutter & Rutter, 2002). Moreover, acceptance also is a positive indicator of better self-care and better mental health (Helder, et al., 2002). At the same time, it is not sure whether what direction this causation exists, and what yields the other. However, it is safe to say that the primary goal of health care providers must be to motivate patients with diabetes towards active problem-focused behaviors instead of passive behaviors and seek to enlarge the overall social help and connectivity.

According to Bryan J. Weiner, bio-medical strategies and patient-centered strategies constitute as two important categories of treatment interventions for diabetes, each having its own set of adoption and implementation processes as well as challenges (Weiner, Helfrich, Savitz, & Swiger, 2007). They define bio-medical strategies as those that focus on health care providers and concern themselves with altering the structure and processes in clinical care (e.g., performing foot examinations or using flow sheets to track diabetes care). Patient-centered diabetes strategies are those that target knowledge, skills, or motivation of the patient and work towards enhancing them (e.g., teaching health skills, self-care cues or offering nutrition therapy). It was assumed that primary care providers might have better familiarity and experiential and practical resonance with bio-medical interventions. As a result, these interventions might be better accepted, adopted and implemented with fewer known barriers than patient-centered interventions. However, the findings of the study highlighted that medical care units routinely face the challenge of translating medical knowledge as far as adopting new strategies is concerned. Primary care providers attend to a large number of diabetic patients every day and are able to do it at a fast pace despite lack of staffing and resources. The general every-schedule and a



commitment to cater as many patients each day as possible prevents them from indulging in literature or updating their practice in accordance with latest findings and research. There is also very little time to make structured analysis or decision-making through collective deliberation about logistics or feasibility of adopting a new evidence-based strategy. Many care providers expressed how the information presented in latest researches is too complex, long and impractical and generates delays as well as confusion. Providers learnt about new interventions through traditional sources like journals and associations, however did not regularly update themselves with relevant literature. Resultantly, they incurred bad decision making and logistical miscalculations when assessing or considering the adoption of a new intervention. Hence, policy makers and government health plans must utilize better tools, models and means to ensure effective dissemination of information and research findings. Proponents of evidence-based strategies should explicitly present their research findings and make relevant literature accessible and easier to understand. The health-care providers must routinely be brought in the loop to refresh their knowledge and update their strategies.

The researchers of this study also witnessed issues related with implementation of adopted strategies. It was noted that for a swift and successful implementation, the innovative strategy as well as the organizational set up had to be adapted. Core features of steady implementation were trained staff and personnel, resource allocation and administrative coordination.

The researchers observed that collaboration is necessary for successful implementation, and that once primary care observers gain realization about the importance of steady work flow, effective communication and implementation of mutually reinforcing changes in organizational staffing, a visible improvement in the overall process can be noticed. Proponents of evidence based diabetes care must take it upon themselves to highlight the areas that are critical for implementation and sustained progress. It is regrettable that various well-established frameworks for diabetes care fail to acknowledge this collaborative aspect and role of organizational changes in diabetes care. In this context, Rogers's diffusion of innovation model (Rogers E. , 2003) for example, hinges upon the

assumptions that individual care-providers are able to make independent choices to adopt or not adopt the treatment innovation, that implementing innovation in clinical care did not necessarily require addition or simultaneous organization efforts or support and that benefit of individual innovation use is not affected by whether or not other care providers are using the same innovation. As apparent, these assumptions cannot account for comprehensive explanation of why certain innovations fail despite being done in this manner.

In contrast, Klein and Sorra's innovation implementation model (Klein & Sorra, 1996) is suited for complex, multifaceted strategies and may provide realistic analysis. While case study methods are excellent sources of rich-multi-layered data and are fluid, non-linear and context sensitive, they still pose the issue of broad generalizations (Klein, Conn, & Sorra, 2001). Findings generated by case-studies use be triangulated with more statistically representative cases and samples to increase generalizability.

(Parsons, 1951) and (Foucault, *The Birth of the Clinic*, 1973) (Foucault, *Discipline and Punish: Birth of the Prison*, 1977) in drastically divergent ways, have also had a share of their influence on research in the area of illness, and their writings remain relevant till date. Parsons' theorization of sickness and recovery starts with the idea that a healthy population is needed for a well-functioning productive society, and he viewed physical and mental illnesses as a form of deviance, something which needed to be resolved so that the individuals who have illnesses should resume their appropriate roles in society. Consequentially, the doctor is an agent of social control, who bears the responsibility of analyzing the health of individuals, decides if they are able to fulfil their prescribed social roles, and in case they cannot, the doctor exempts them for a specified period of time to recover. Resultantly, patients carry the burden of conforming to the prescribed medical instructions. An increasing number of scholars have argued that this theory is inapplicable in cases of chronic illnesses and degenerative disease, as patient's recovery from the condition is not possible despite the individual's concern and motivation to seek medical help and advice (Bury, 1997), (Herzlich & Pierret, 1984) (Weitz, 2004) (Zola I. ,

1972). However, the prescribed treatment given from doctor to patient is viewed as a something that could minimize deterioration and prevent complications.

Foucault (1977) purports a sharply contrasting standpoint and offers a context that extends Parson's theorizations about the use of doctor (Turner, 1997). Foucault explains how the individual remains under the over-powering control of the society. He further goes on to claim that doctors and medical experts have specialized knowledge which they regularly use to influence and exert control over their subjects and make sure that they are socially re-integrated according to their desired plan. The two theorists mentioned are heavily criticized for their assertions, however their work is particularly relevant when talking about diabetes (Lupton, 1997). The outcomes of patients' conditions and adherence are greatly shaped by the discourse on medicine that exists (Kleinman, 1980).

As far as clinical perspectives are concerned, controlling or managing diabetes is relatively unproblematic. Patients are diagnosed by clinicians, recommended a health care regime, prescribed insulin therapy, told to keep regular appointments and checkups, advised to lose weight if obese as well as guided about certain lifestyle changes and dietary modifications targeted at controlling the glycemic levels. Diabetic patients are also kept under a check by their care-givers or other health professionals (diabetes nurse educators, for example). Additionally their blood and urine are sampled to ensure whether they are complying with recommended modifications. A lot of work has been done with regards to diabetes control which reads into people's beliefs, attitudes, cultural dictations etc., in an attempt to understand deeply the variables that affect adherence to treatment, medical advice as well as the differences that exist between patients and practitioners' understanding of the condition and its management (Eisenberg L. , 1977) (Kleinman, 1980) (Zola I. K., 1966). This existence of gaps within the understanding of various patients regarding diabetes and its management has meaningful influence on the overall spread and control of the disease and also helps to enhance the knowledge regarding the criticality of introducing behavioral modification routines.

Biomedical professionals understand diabetes as a pathology, something which has a direct consequence for the patients' physical health, however, an increasingly large

number of patients point out to the social equation of the condition, which for them is much more important and problematic. (Cohen, Reimmer, Smith, Sorofman, & Lively, 1994) (Hunt & Arar, An analytical framework for contrasting patient and provider views of the process of chronic disease management., 2001) (Loewe & Freeman, Interpreting diabetes mellitus: Differences between patient and provider models of disease and their implications for clinical practice, 2000) (Loewe, Schwatzman, Freeman, Quinn, & Zuckerman, 1998). Patients associate loss of support from family and friends, loss of social connections, connection with land and work, loss of job, appetite, sexual problems and infertility, all of which has lasting influence on patient's social relationships and also his or her own psychological health. The existence of such socio-cultural forces and their influence on patient's condition causes medical professionals to perceive this as non-compliance, whereas diabetic persons constantly struggle to control and mitigate the social cost and barriers, and the influence of these on their relationships. Hunt and his associates explained that the biomedical approach towards diabetic patients focuses solely on achieving the optimal blood sugar level and motivates patients to exercise, diet and control their blood sugar levels (Hunt, Arar, & Larme, 1998) (Hunt, Arar, & Larme, 1999). However, their Mexican patients has a primary goal of attaining social integration with diabetic control in their daily lives. People with lesser degree of control in their daily lifestyles are more likely to perceive themselves unable to manage their condition and related risks. Similarly, Thompson and Gifford (2000) explain the challenge in the context of urban Australian Aborigines where diabetes is seen as a complication that results from loss of control over their everyday activities, imbalance of life and loss of connection with land and relatives (Thompson & Gifford, 2000).

Following the same idea, Broom and Whittaker (2004) also write about there exists some level of discordance between patients and their practitioners in the rhetoric of control amongst Anglo-Australians with diabetes (Broom & Whittaker, 2004). This discordance also spells out how the patients understand and negotiate their own identity and their social ties and kinship through a language of control. Studies conducted in Thailand also take into account the health model related dissonance and consonance that permeates the patient-practitioner relationship. A study on menopause by Chirawatkul and Manderson

(1994), found how patients and doctors in Northeast Thailand constructed menopause completely differently (Chirawatkul & Manderson, 1994). The village women considered it as a simple, straightforward, natural process of biological progression, whereas doctors saw it as a physiological event that requires aid and treatment. A study on leprosy also saw how medical model views it as a bacterial infection, whereas in lay terms, leprosy was believed to be associated with heredity, dangerous food, sin, karma and humoral disorders (Neylan, Nelson, Schauf, & Scollard, 1988) (Srirak, 1997).

The researchers explored the discrepancies that were thought to divide the medical opinion and lay understandings of diabetes within the Thai culture. They paid special attention to the idea of control and studied the manner in which patients tried to integrate the control of their condition in their day to day lives. The researchers explain how term 'control' plays an important role in the ideas and discourse that exists regarding diabetes. Control connotes power and is premised on influence or authority resting with one, usurping the freedom of those subjected to control. In medical terms, control is implied through behavioral patterns and recommendations (Conrad & Schneider, 1980). Conrad explains how control in the medical world is exercised and enforced, and notes how the very interpretation of disease or illness, the treatment defined, the ideal blood/sugar levels outlined, the interpretation of signs and symptoms, the diagnostic procedures, classification of illness, defining behaviors, outlining protocols, tests and therapies, provision of medical information, drug administration, risks outlined, the surgery or procedures being made mandatory, the counseling or advice the patient receives (Conrad, 1992).

Discourse in biomedical models also clearly mention control in reference with compliance, while at the same time making apparent the system of hierarchy that is sitting at the heart of this context which is this: the patient is subservient to, under the oath to comply or submit to the recommendation of the expert (Haynes, 1979) (Hulka, Kupper, Cassel, & Mayo, 1975). The researchers explain that how the Thai word for control, *kuabkum*, is a compound of two separate verbs: *kuab* and *kum*. *Kuab* literally means to merge, join, put together or connect whereas the word *kum* means to take

control or charge (Haas, 1964). In addition to connoting power, the word *kum* in Thai implies authority, where the one who has control is viewed as more powerful while the one on whom power is exercised is perceived as weak, damaged or submissive. The researcher of this study focused on how control is understood in Thai culture amongst diabetic persons. To see how diabetic patients in Thai culture, the researchers first tried to see what their condition meant to them in context of their every-day lives. The sufferers of chronic illnesses, according to (Charmaz, 1991), see their illness a disruption, an interruption in their living and activities, and an intrusion in their lifestyles. When patients look at their illness as an interruption, or something which is synonymous to an inconvenience, they look towards remedy or recovery. During the illnesses' incipient form, there exists an anticipation of hope on part of the patients, where they feel that recovery is possible or they can be close to a complete recovery, and also where they feel motivated to maintain an equilibrium and avoid regressing into complication. The patients tend to see their illness as something transient or temporary, something which allows them to view their future with uninterrupted positivity. They no longer feel obliged to adjust or transform their perceptions of what future would look like because for them, treatment or recovery is near. This feature however is common with acute illnesses, and not chronic conditions. However, an intrusive illness presents a permanent risk, and requires a major readjustment and shift in perspectives and belief system as well as require special physical care, and continuous time and effort. Patients tend to not only acknowledge the disease but also accommodate its effects on their lives and adapt their activities and schedules around it. However, the researchers suggest that at a point when illness begins to be immersed in the lives of the patients, and entire life begins to be loosely constructed around it, without diabetes defining the core features of this life, it turns into an acceptance of circumstances and diabetes may not dominate the life of the patient (Charmaz, 1991).

Diabetes along with other chronic illnesses lie flexibly on a spectrum of immersion and intrusion. It varies from individual and his or her own life events and circumstances, whether diabetes defines their life or whether it is structures around diabetes. The medical practice, with its prescriptions and limitations acts as a way to control patients

and is also a way for medical experts to ensure whether the diabetic condition remains intrusive or immersive. Essentially, this ability of doctors to define the role of disease, or its overall perception held by the patient gives the health expert their power, authority and professional hegemony over patients. The patients expressed that at the incipient stage when diabetes remained undiagnosed and invisible from their lives, the participants did not perceived it as intrusive. However, the moving of diabetes to the foreground or background, happened gradually and with time. This at the same time affected patients' self-understanding of the level of control that they had over their conditions as well as the trajectory of their disease. The researchers noted, that the most critical aspect of the diabetic patient was blood sugar level, however patients did not feel the need to control it or its related risks that could prolong or worsen their condition. The element of control enhanced as the condition moved from being visible to invisible, or intrusive to immersive with time. For instance, it was observed that the need to see a doctor became pronounced, or the need to control blood sugar level arose when the disease worsened or complications developed. It was seen that participants took great care to exercise control at these levels for instance by discontinuing sweets as they understood it as the most efficient way to normalize their condition.

Patients who live with chronic illnesses like diabetes have various aspects of their lives affected, and patients have to impose control on most of these aspects. However, the researchers explain how the idea of control that patients exert in their lives is very different from the medical understanding. The influence of control and its interpretation within patients take much from the Buddhist philosophy, and Thai culture and values that operate through their everyday life. (Keown, 2001) (Payutto, Prayudh, & Olsen, 1995) (Podhisita, 1985). The efforts of the patients towards regulating their blood sugar level and accommodating the recommended lifestyle alterations followed the medical advice as per the medical rhetoric, however it was seen ideas of control were all derived in some way or the other by Buddhist virtues and morality, Thai cultural hierarchies and the idea of maintaining harmony by following the norms of behaving appropriately on day to day basis.

The changes accommodated by patients with diabetes, and their representation of these alterations to their care-givers are all influenced by the central values which shape the mode of interactions. For many Thai patients suffering from diabetes, the medical adjustment is less appealing and often rejected, in favor of cultural and Buddhist philosophy of harmony and resistance to authoritative dictations. This does result in a conflict, which has a lot of impact on social relationships of patients in connection with their care givers. The conflictual rhetoric of patient and doctor's understanding of control and their impact on patient's psycho-social health and adherence suggests that new ways of conceptualizing patient-practitioner interactions is needed. Health experts must realize how there exists a difference in the manner through which patients and doctors construct the disease and its control. It is incumbent upon the practitioner is acknowledge the various interpretations and cultural moorings that weave through the patients mind and influence his understanding of his own condition. The gap in patient-doctor communication exists because of the medical culture of hierarchy that mediates the patient-practitioner relationship. This causes patients to be subjected to dissonance and makes them reject the dictations of control by medical experts. It is pertinent to understand and acknowledge these conflicts to facilitate health promotion, and health education during consultations.

## **2.6. Theoretical Framework**

Issues related with/to delivery of primary health care has been a crucial focus of many researchers that have been exploring and explaining the information exchange, success of patient's compliance/adherence and its impact (Tuckett & Williams, 1984) (Barsky, et al., 1980). Different medical anthropologists have intellectually differentiated the layman definitions of ill health with biomedical explanations and processes of diagnoses and treatment of diseases (Eisenberg L. , 1977) (Fabrega & Silver, 1973) (Kleinman A. , 1980). The biomedical approach overwhelmingly emphasize on the biology and physio-chemical terms that shrink the understanding of what is social, cultural and psychological in ill health (Kleinman, Eisenberg, & Good, Culture, illness and care: clinical lessons from anthropologic and cross-cultural research., 1978)



According to the champion(s) of explanatory models (Kleinman et al, 1978), biomedicine dominantly consider biological as more real and clinically significant as compared to the other part of the ill health (i.e., social, cultural and psychological data). The disease illness dichotomy brings research area(s) forward that may focus on how much one of the above mentioned shares in the episode of ill health. Disease, though generally considered a wider phenomenon is actually the other way. The illness whereas, is wider, diffused, complex and is patterned by socio-cultural factors.

Kleinman used explanatory models in medical care, especially to microscope diagnosis and treatment (both success and failure) by bisecting patients and providers perspective (on the same disease and its treatment). Several other authors have endorsed the practicality of the explanatory models towards understanding of adherence issues and comprehension to physician's instructions. The socio-cultural and psychological construct of ill health is important analysis as stated by Engel as "the meaning of the patient's report in psychological, physiological and biological terms". Social and cultural origins are an important discovery that affect the overall adherence to the treatment such as trauma or stress, domestic responsibilities and occupational functions etc. (Zola I. K., 1966)

Explanatory model is a central concept for exploring and resolving public health problems in medical anthropology. It brings an appropriate reaction to a particular disease by patients in a specific community. For example, if drug use is understood as a willful, deliberate, criminal activity, then the appropriate response would be to punish drug users as criminals (for anthropological work exploring the criminalization of addiction, (Spradley, 1970) (Bourgois, 1995) (Becker H. , 1973) (Bourgois & Schonberg, Righteous dopefiend, 2009). On the other hand, if addiction is perceived as a disease, as a disorder of the body or of the mind over which each person has limited control, then the appropriate response would be to treat that individual as a patient, to provide pharmacological or psychological therapy (for anthropological work exploring addiction as a medical disease, (Carr, 2010) (Garcia, 2010) (Bourgois, Disciplining Addictions, 2000).

It is important to distinguish that explanatory models can be shared between groups or individuals, such as the widely held belief that a cold or other such minor illness can be caused by a draft or a chill in the room. On the other hand, it is also emphasized that different people (individuals) may have contrasting perceptions towards the same disease. *The Illness Narratives* (1988) by Kleinman, shares the example of William Steele, a man who began suffering from severe asthma following his fortieth birthday. While Mr. Steele and his doctor both agreed on his diagnosis (asthma), they disagreed about the underlying cause. Mr. Steele believed that his asthma was triggered by the stress of his fortieth birthday, whereas his doctor understood asthma as an illness whose “ultimate cause is unknown.” (Kleinman, 1988, pp. 123-4). Despite the significant overlap in the explanatory models held by Mr. Steele and his doctor, this minor disagreement had significant consequences. Believing that his doctor never fully understood the causes of his illness, Mr. Steele began taking his medication improperly, particularly during times of personal stress, which resulted in making him much sicker (Kleinman, 1988, pp. 125).

It is very important to note that the biomedical approach is, itself, an explanatory model. It serves as both instruction and justification for particular actions taken in response to human illness. In Kleinman’s words, the modern medical bureaucracy and the helping professions that work within it...are oriented to treat suffering as a problem of mechanical breakdown requiring a technical fix. They arrange for the therapeutic manipulation of disease problems in place of meaningful moral (or spiritual) responses to illness problems (Kleinman, 1988, p.28). To put it another way, Kleinman argues that the biomedical model declares medical problems to be physiological or biochemical in nature and that treatment ought to be directed towards the individual organism. This feature of the biomedical explanatory model is often called medicalization.

Nagarkar (Nagarkar, 2012) stated that there is dire need of using medical anthropology as a major contributor in public health trials and interventions, health education and other related initiatives. Medical anthropology in public health especially focusing on health education, trials and interventions answers to epidemiological transition including trends in infectious diseases and non-communicable diseases. Nagarkar also pointed out useful

theoretical contributions by anthropologists in public health including (Paul, 1955), (Murdock, 1952) (Murdock, *Theories of illness: A World survey*, 1980) and (Kleinman A. , *Writing at the margin: Discourse between Anthropology and Medicine.*, 1977). Most important and used model is by Kleinman that view illness through the lens of cultural explanatory model as compared to traditional perspectives (imbalance of forces, supernatural forces or sorcery etc.) in anthropology. The Explanatory model was articulated by physician-anthropologist (Kleinman A. , 1980) (Kleinman A. , *Rethinking psychiatry: from cultural category to personal experience.*, 1988a) (Kleinman A. , *The illness narratives: suffering, healing and the human condition.*, 1988b) that examines the immediate context of treatment, progress of a malady and how it may be treated.

Treatment programs especially for Diabetes as shared by (Hernandez, 1995) may be evaluated in detail as patients have an altogether different view towards treatment and maintaining life with diabetes. Similarly (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994) found that patients hold a different perspective in their explanatory models of diabetes progress and treatment. However there is criticism on explanatory models approach (Young, 1982) that includes prime focus on individuals, and patients may give different accounts of the same sickness at the same time and may also give different accounts at the same time (but that may also be used and analyzed as separate illness perceptions for each individual).

A study (McSweeney, Allan, & Mayo, 1997) shared that Explanatory models are valuable that may explore the inter-subjective realities produced out of certain social, historical and cultural factors towards certain diseases. The explanatory models by Kleinman (1980) captures both individual and group understanding. Earlier researches also validates the usefulness of the above mentioned in understanding the health seeking behavior of the patients by documenting health seeking activities and how decisions are made towards treatment. Explanatory models of illness are embedded in the foundation(s) of social construction of reality. Lay perspectives and paradigms of illness may have an altogether unique and different view towards disease and its treatment. Patient's episode of illness explains how the choice and evaluation of treatment was made. Such

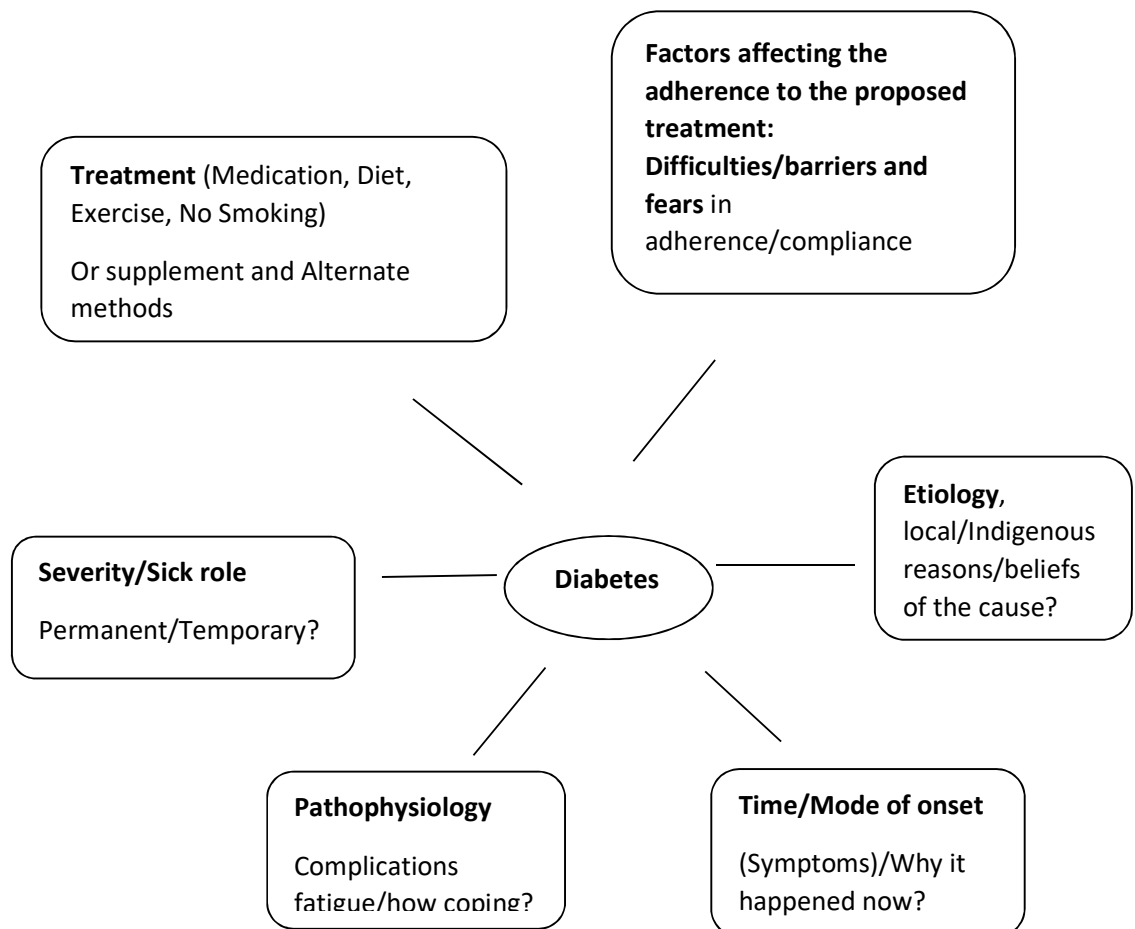
explanations differs from provider's perspectives and inform the gap that may be filled by making any intervention culturally sensitive. (Miller N. H., 1997) (Luyas, 1991) (McSweeney J. , 1993) (Blumhagen, 1982). Principal model(s) that may help understand the context is Explanatory Model (Kleinman, 1980, 1988b).

Four key theoretical approaches in medical anthropology were also discussed by (Farmer & Good, 1991) that included meaning centered tradition which mostly rests with explanatory model. The prime focus of the said approach explores the culturally constituted illness realities. Folk beliefs was also discussed as an applied tradition and it rely on the health beliefs model. The debate also touched upon cognitive structure sand critical medical anthropology.

Kleinman (1980) also proposed that incongruence between practitioner's and client's explanatory models negatively correlates with patient outcome variables such as compliance, satisfaction, subsequent use of health care facilities, treatment response and reporting of untoward side-effects of treatment. For example, in a study of models of hypertension, (Blumhagen, 1982) found that 72% of his sample had "Hyper-Tensions," an illness they saw as characterized by excessive nervousness caused by untoward social stress. These views were clearly different from those of the practitioners he interviewed.

The present study adopted the patient's explanatory model to explore the patient (individual) perceptions including the episode of the disease and adherence to the treatment of the diabetes as offered to them by the RHC *Chak* 104 NB. The study particularly explored the socio-cultural factors that shapes the general perception towards the disease of diabetes and its adherence to the proposed treatment (i.e., medication and lifestyle change), and also factors from physical environment that influences the process towards diagnosis and treatment (and its adherence). The physical environment included both indoor and outdoor environment of diabetics. The study also explored the socio-cultural factors affecting the patients to absorb the counseling for life style modification and treatment adherence. Hence the recommended preventive health action is explained if the individual beliefs are modified by support system otherwise factors creating barriers

to achieve the recommended treatment (medication and life style change) for type 2 diabetes patients in the said locale.



The model sketched above elaborated the progress of malady that may be used to validate the information collected from the patients in different above mentioned categories. The explanatory models of illness is operationalized as below:

**Etiology:** was operationalized as towards the understanding of how this disease has happened to the respondents (patients)? Also local/traditional and indigenous reasons to

understand the cause of diabetes? In this case it encompassed various influencers including economic pressures, social incidences etc.

**Time/Mode of onset:** was operationalized as to understand patient's perspective on why it has happened at this point of time in their respective lives? How did they learn about the symptoms? How did they relate symptoms with diabetes as a disease? How symptoms were interpreted? How did individual patients ask for peer advice (or any other) regarding the symptoms?

**Pathophysiology:** was operationalized as to understand the diabetes related physical problems, also to interpret other social problems related to diabetes? How patients perceived complications and physical fatigue? How it hampered their daily role(s)?

**Sick role:** was operationalized as to understand how patients adopt the sick role of diabetes i.e., is it permanent? Temporary or transit? How certain social roles are being compromised (if any)? How patients cope with it during their daily roles?

**Treatment:** was operationalized as how patients got diagnosed clinically and are being offered care package (i.e., medication and lifestyle change tips/education)? How did they end up getting diagnosed by a health facility? Who influenced that? Other treatment methods being used at the local level? How other treatments are being influenced? How it hampered the overall adherence towards clinical care package offered at the health facility?

**Factors affecting the adherence to the proposed treatment (Difficulties/barriers/fears):** was operationalized as how certain socio-cultural factors influence that may create non-adherence or compliance issue in achieving the treatment targets? What are the fears that may influence patients to try alternate methods? Other challenges that hampers the overall adherence to the treatment.

### 3. METHODOLOGY

The researcher lived (mostly in the year 2016) in the locale for the collection of primary data and to participate and observe the factors that may affect and influence the adherence. The researcher also did preliminary fieldworks in the mid summers and winters of 2015. The idea of preliminary research was to construct a better understanding of the locale before the actual stay in the village for data collection.

The researcher not only lived in the community but also worked/met closely with the staff of the intervention health facility (i.e. rural health center *Chak 104 shumali*). The connections were made in the year 2015 especially with the medical officers of the RHC and the responsible paramedic (who did patient counseling regarding lifestyle change and smoking cessation). Later in 2015, the paramedic became the key informant and did help identifying the registered patients of type 2 diabetes in the intervention health facility. The paramedic also shared the copies of the counseling tools used for the patients' education. The doctors of the RHC shared the desk guide used for the identification, diagnosis, prescription and follow up of the diabetes and hypertension patients. The researcher also made acquaintances with the field officer of the research organization (program partner of the intervention) who helped in enhancing the understanding of the regimen (as instructed for the diabetics), tools (used for counseling and messages) and a broader context of the program (i.e., non-communicable diseases and mental health).

Since the research inclination was strongly falling in the realm of medical anthropology and the design was exploratory in its nature to understand the contextual issues of the patients, the researcher used various relevant tools discussed below. Medical anthropology is commonly involved in exploratory research studies. Also, most of the research in the domain of medical anthropology is observational. Broad classes of observational designs are cross-sectional, longitudinal, and case-control studies. This research however was cross sectional in design and is also common in medical anthropology in which the data is collected at one point in time. Many ethnographic researches are cross sectional in terms of their design. (Gravlee, et al., 2009)

The intervention health facilities (as per the data of the research organization and national program) included in the pilot trial were in total seven in number. These included including:

7. *Bhagtanwala*
8. *Laliani*
9. *Farooqa*
10. *Babhra*
11. *Sahiwal*
12. *Miani*
13. 104 NB

Table 5 Number of Registered Patients per Intervention health Facility

<b>Health Facility</b>	<b>Registered Patients</b>	<b>Percentage</b>
SAHIWAL	43	7.4
<b>104NB</b>	<b>71</b>	<b>12</b>
LALIANI	45	7.7
FAROOQA	30	5.1
BABHRA	38	6.5
MIANI	36	6.2
BHAGTANWALA	44	7.5
<b>Total</b>	<b>307</b>	<b>100.0</b>

The researcher collected the required relevant data from the research organization (i.e., number of registered patients per intervention site). The rural health center 104 NB outnumbered other health facilities in terms of its registration of the diabetics (it is important to mention that the intervention offered no outreach activity, the patients were identified and diagnosed on routine/normal). The researcher then used the RHC as an entry point to identify the registered patients with the help of the paramedic. The basic data of the registered patients were found on the non-communicable disease (NCD) card.



The research focused on the catchment area of the above mentioned RHC where patients were categorized into two main categories i.e., adherents (male and female patients) and non-adherents (male and female patients) were categorized as the main respondents.

### **3.1. Sample of the study**

The researcher used the district health information system (DHIS) initially to understand the ongoing scenario regarding the non-communicable diseases in particular and performance evaluation of the health facilities in general. The DHIS has given an ‘A’ grade to RHC 104 NB on the basis of its working/functioning and commitment of the staff. The RHC 104 NB was found to be in grade A with other 13 health facilities in district Sargodha. The health facility had 71 registered patients of diabetes (who were offered the diabetes care package) as per the intervention.

The researcher took the data from NCD cards at RHC 104 NB to further identify the respondents from the registered patients. The researcher met (informally) all of the registered patients (male and female). The patients were divided into four categories for the ease and understanding of the selection of research/study samples as given below:

14. Adherent females
15. Adherent males
16. Non-adherent females
17. Non-adherent males

The researcher also did a detailed case study of *Chak Mangla* water (after the confirmation that almost all of the respondents used it as a support/supplement treatment to cure diabetes). The case study included the in-depth interview of the owner (of the *dera*<sup>18</sup>). The researcher did make multiple visits and spent time (from morning till

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18 Dera: a tent, or a camp. *Dera* is a sitting place mostly for the male members of the Pakistani society. *Dera* is a generic term for the camp of a saintly figure located outside the influence and territory of the social space of a community. Its origin in Punjab could be traced back to the Nath tradition of Gorakh Nath. *Deras* substantially differ from each other in terms of various traditions,

evening) over a few weeks, since there was no place (such as hotel, hostel or public arena) to stay for the night.

The researcher interviewed a total of 40 registered patients (i.e., ten from the each above mentioned categories). The researcher also made a thick case study on the *Chak Mangla* water (keeping in view the importance and usage reported by all the respondents) along with other communally advertised and culturally endorsed treatments. The researcher also focused on support and alternate treatment methods and processes.

## **3.2. Data Collection**

The collection of data in medical anthropology may be categorized in three major categories including participant observation, interview methods and systematic observation. Participant observation is considered as the base of the data collection in medical anthropology, which also shares the legacy and practice of the parent discipline. This research used participant observation as a key approach to understand the overall socio-cultural situation and practices along with in-depth interviews of the registered patients and case study of *Chak Mangla* water (as a support treatment used by all of the respondents). The current study not only took the verbal consent from the respondents and also from the concerned departments including District Head Quarters Sargodha, Rural Health Center 104 NB and implementing partners.

### **3.2.1. Participant observation**

The researcher by staying in a room (given/shared by the paramedic of RHC 104 NB) observed closely the general lifestyle, diet patterns, physical activity and treatment choices for type 2 diabetes. The patients started knowing the researcher well due to his interaction with the staff of the RHC 104 NB.

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beliefs, and practices. Nihang *deras*, for example, cover all the places related to Nihangs (Sikh warriors) (Singh & Fenech, 2014).

During the field work, the researcher not only participated (mostly with the male patients) in the daily activities but also observed the daily routine of the female patients with the help of LHW (observed mostly elderly female patients daily chores). The researcher spent full day(s) with different male diabetics starting from waking up early and meeting on *fajar* prayers or outside the mosque. The researcher also visited their respective houses and workplaces (after the verbal consent). The researcher also observed how patients spend their days in general including their diet pattern, mode of transportation, expression towards clinical treatment, peer group, seeking supplement or alternate treatment and especially coping and managing the label of diabetic. The researcher also learned about the episode of the disease by spending time with different patients (mostly male and elderly female).

### **3.2.2. Key informants**

The current study had two key informants (i.e., Lady Health Worker<sup>19</sup> and RHC paramedics) who helped understand the catchment area of RHC 104 NB. The key informants greatly helped in interpreting the local terms, issues and other related challenges. The key informants also assisted in correctly identifying the diagnosed and registered type 2 diabetics (at RHC).

The researcher used to meet the key informants daily (mostly after their office hours). The paramedic (male) was more conveniently available in the early and late evenings. However the LHW sometimes had official duty to perform even in the evening (especially in case of emergency related to mother and neonatal). Both key informants

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<sup>19</sup> Lady Health Worker (LHW): As part of the government of Pakistan's National Program and Primary Health Care, the Lady Health Workers (LHWs) programme was started in 1994 to provide health education, promote healthy behaviors, supply family planning methods, and provide basic curative services. The program participants were consisted of all females, and had duties of monitoring the health of pregnant women, monitoring the growth and immunization status of women, and promoting family planning in their working communities. All the women (usually ages 20-50) were expected to have an 8<sup>th</sup> grade education, and be a permanent resident of her work site. They were given health care training on the basics of primary health care through classroom and clinical practice, and are also given a refresher course monthly. The program covers approximately one third of the target population, and overall indicators of the population showed slightly better health than the national average.

immensely supported the entire field work and also helped articulating different questions from the respondents (though the researcher did learn the specific *Shahpuri* Punjabi<sup>20</sup> dialect in 2015). Both key informants help translating and interpreting the indigenous terms and also helped relating it with the domain of the research.

### **3.2.3. Socio-economic survey**

The researcher used socio-economic face to face survey as an opening meeting with the patients. Although there is a debate on face to face administration of survey, however (Schober & Conrad, 1997) and (Krosnick, 1999) discussed that more conversational style of administering survey may bring more accuracy. It may be also be considered as an advantageous option for illiterate or non-literate, or people who does not understand the questions clearly.

The researcher confined the survey as cross sectional and focused on the basic information of all the patients registered at the above mentioned rural health center. The closed ended questions included age, gender, schooling, family income, marital status, family type, registration information with the health facility. The survey also helped categorizing the patients in terms of their age brackets and were planned to interview accordingly.

### **3.2.4. Informal interviews**

The researcher used the informal technique to interact with the patients so that they may discuss the issues more openly and less formally. The researcher had informal interviews with nearly half of the patients so that an acquaintance may be developed for the upcoming in-depth interviews. The researcher kept in mind the busy schedule and routine of both the male and female respondents. The informal interviews also greatly helped in

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20 Shahpuri Punjabi dialect: Shahpuri dialect (also known as Sargodha dialect) is mostly spoken in Pakistani Punjab. Its name is derived from former Shahpur District (now Shahpur Tehsil, being part of Sargodha District). It is spoken throughout a widespread area, spoken in Sargodha and Khushab Districts and also spoken in neighbouring Mianwali and Bhakkar Districts. It is mainly spoken on western end of Sindh River to Chennab river crossing Jehlam river.

designing the in-depth interview guide. The researcher also assessed the key areas and probe points to be covered during the in-depth interviews.

During the research, the researcher shifted the focus on informal chats that not only cultivated valuable information but also activated the respondent to voluntarily share the issues and knowledge regarding the topics of the discussion.

### **3.2.5. In-depth Interviews**

An in-depth interview guide was designed based on the preliminary fieldwork (in 2015) and informal interviews with the patients. The researcher did ask for the permission of interview from each respondent. The in-depth interviews lasted from one hour (at least to around two and a half hours). The variation in the duration of the in-depth interviews was due to the explicit nature of few respondents.

Most of the respondents shared the information during the in-depth interviews at their respective house or work place. The respondents were not restricted and were allowed to respond to any question for as long as they want to. The researcher also took verbal consent before recording the interview(s). The researcher did the same before taking each and every picture in the locale (especially with the respondents).

### **3.2.6. Tools**

Following tools were used during the field work:

#### **3.2.6.1. Interview Guide**

An interview guide was designed based on preliminary field work (in year 2015) and interaction with different stakeholders and community members. The tool was designed keeping in view the general framework/model adopted from the explanatory model of patients.

The interview guide was thematically divided into below mentioned themes:

**Etiology:** was focused to explore the understanding of how this disease has happened to the respondents (patients)? Also local/traditional and indigenous reasons to understand the cause of diabetes? In this case it encompassed various influencers including economic pressures, social incidences etc.

**Time/Mode of onset:** was focused to explore and understand patient's perspective on why it has happened at this point of time in their respective lives? How did they learn about the symptoms? How did they relate symptoms with diabetes as a disease? How symptoms were interpreted? How did individual patients ask for peer advice (or any other) regarding the symptoms?

**Pathophysiology:** was designed to focus, explore and understand the diabetes related physical problems, also to interpret other social problems related to diabetes? How patients perceived complications and physical fatigue? How it hampered their daily role(s)?

**Sick role:** was designed to explore and understand how patients adopt the sick role of diabetes i.e., is it permanent, temporary or transit? How certain social roles are being compromised (if any)? How patients cope with it during their daily routines and roles?

**Treatment:** was focused to explore as how patients got diagnosed clinically and were offered care package (i.e., medication and lifestyle change tips/education)? How did they end up getting diagnosed by a health facility? Who influenced that? Other treatment methods being used at the local level? How other treatments are being influenced? How it hampered the overall adherence towards clinical care package offered at the health facility?

**Other factors influencing the adherence to the proposed treatment (Difficulties/barriers/fears):** was designed to explore how certain socio-cultural factors influence that may create non-adherence or compliance issues in achieving the treatment targets? What are the fears that may influence patients to try alternate methods? Other challenges that hampers the overall adherence to the treatment.

### **3.2.6.2. Observational checklist**

An observational checklist was also designed to focus on what to observe during the field work. This included the general environment of the village with a special focus on diet related activities (food stalls, fruit shops, restaurants etc.) and exercise (space). The hospitality trends and diet change in the holy month of Ramadan were also part of the checklist.

The checklist also included advertisements, banners and wall chalking in the community, and general outlook of the rural health center. The checklist also included basic profile of the village (through multiple indicators such as attire, living standards, climate etc.).

### **3.2.7. Case study (of *Chak Mangla* water)**

The information from the above mentioned clearly indicated the importance and fame of the *Chak Mangla* water (a supplement/support treatment especially for diabetes). The researcher found that all of the respondents did try the water at least once to cure the diabetes (as it is commonly known and famed to cure the disease).

The researcher visited the *Chak Mangla* (not too far from the locale) with a respondent (who was a regular visitor) in 2016 to have an in-depth understanding of it. The researcher documented the entire case by interviewing the owner as well as informally chatting with the general public who come from different parts of Punjab and also other provinces.

### **3.2.8. Data analysis**

The data was collected with the help of a thematic interview guide carefully designed during the preliminary field work (that included informal interviews with health care providers, patients and other community members). The themes were adopted from the patient's explanatory model.

The already adopted themes helped sorting the responses of respondents under each theme. However, the sub themes emerged from the focused theme of ‘Treatment’ as common/similar responses/answers and reactions.

The participant observation (as stated above) also supported in analyzing the factors other than the perceptions of the respondents. The observations were used to logically associate the responses of the respondents under identified and emerged themes and sub-themes.

The responses were initially transcribed under each theme. The similar responses under the focused theme were used to create sub-themes. The overall approach (as discussed in the theoretical framework) was to understand, draft and analyze the episode of illness. The data was analyzed accordingly in an episodic manner starting from its etiology till factors affecting the proposed treatment at public health facility. The important statements of the respondents were included as verbatim in each theme.

#### **3.2.8.1. Transcribing of data and completing of field notes**

All recorded and hand written materials of conversations, interviews were transcribed and field notes completed for all observations, conversations, basic profiles, and case study (of *Chak Mangla* Water). Documentary evidence was also summarized from the data recorded at the health facility (through non-communicable disease card). Time was spent listening and transcribing recorded interviews and reading the field-notes. Field notes taken in the course of observations were completed. The transcripts and documentary evidence were typed accordingly. The transcripts captured features of conversations such as emphasis, speed, tone of voice, timing, and pauses. These elements made up the crucial aspect of interpreting data, given the multiple events that produced them. Reading and completing the transcripts and making notes from them permitted to identify ideas, make observations, and get insights and inferences. Researcher organized the data and sorted out all the materials needed to enable getting on with the initial analysis. Once each transcript was read and classified, it was dissected, pulled apart, and scrutinized transcript by transcript to enable the full understanding of the nature of the data collected.



### **3.2.8.2. Coding**

The coding process was a mechanical way of assigning names to portions of text. The coding involved reading through the data, identifying themes and patterns, and placing them under headings or brief descriptions summarizing what they mean. Sections of text that related to a code were cut and pasted into the document created to represent that code as the researcher worked through each transcript. It enabled to build up a logbook of relevant text related to each created code. The source of each text that is collated to the codes was labelled so that researcher could easily refer back to it and understand the context in which the text was produced. Some text fitted within more than one code. In the first reading of transcripts, the codes were general. Subsequent reading enabled the splitting of the general codes into more specific ones. Through the coding process, similar portions of data were pulled together. Codes provided a fast snapshot of similarities, differences, patterns, themes, categories, concepts, and relationships from huge amounts of data sets across transcripts. The codes permitted the linking of initial transcripts and field notes to subsequent ones. These codes were the main emerging ideas from the data. Computer software was not used to code data. Rather manual coding using both pen and paper to code manual transcripts was conducted and the computer to code electronic transcripts. A logbook of codes was developed and stored electronically and manually. Researcher wanted to try an experience that could be documented and shared with people who do research in settings with limited access to technologies. A multistage analysis was done by sorting and pulling the themes together and verifying them to get emerging details.

The analysis draws a bit on (Garfinkel, 1984) but the fieldwork sought to build confidence with the participants without considering his approach. The analysis approach is a combination of ethno-methodologies but with greater emphasis on grounded theories emerging from the data. Hence, content and thematic analyses form the basis of the data management and analysis. The analyses were overlapping multiple stages. The data were divided into several groups which differed in depth. Further processing of data was done to identify themes from the contents of texts and probing into the meanings of the themes. Each stage was repeated over and over as the data collection process evolved. Data

analyses began at the moment the first transcripts of field notes from observing care seeking consultations were available through the fieldwork process and intensified after fieldwork. The analyses comprised a primary analysis stage and profound analysis stages, with supplemental data collected at subsequent stages, then further analysis. The primary analysis for this study included preliminary recognition of broader themes and the subsequent detection of themes and sub-themes that required more precise analysis. This widened the meanings inherent in texts to overcome any distortions. At the primary analysis stage, the analysis of themes and the development of concepts were established with more accuracy. The profound analysis stage in this ethnography included repeating recognition of themes considering the dynamics that followed subsequent data collection and subsequent analysis. The contents of transcripts were reviewed and analyzed as data collection continued. This process permitted the amendment of the questions that were asked to enable more data gathering as fieldwork evolved. This stage took into account the supplementary data obtained at the previous and subsequent stages of fieldwork. It enabled the detecting of themes that required more precise analysis and the identification of dynamics in themes and concepts leading to the collection of supplementary data. These analyses gradually built up into a theory grounded in the data from which the themes and concepts emerged. The themes and concepts revealed relationships and differences in themes according to the categories of research participants. A logbook about the themes was kept alongside the transcripts. With the logbook the researcher started having an emerging story that revealed ideas, more insights, and explanations. The themes in the logbook were followed up in subsequent fieldwork activities to look for alternative explanations and evidence to support the ideas and interpretations. Further fieldwork permitted the verification of the themes and the identification of new themes and sub-themes as well as evidence that might not support them. The reading of transcripts and comparing of themes and sub-themes were done several times until a point where it made sense was reached and arguments were produced that addressed the research objective.

The analysis led to obtaining lay definition of the concept of diabetes and how the lay definitions influence the way people seek diabetes care. The definitions are grounded in

people's thoughts and behavior as revealed by the ethnography. The shifts in meanings illustrate a multistage profile that provides the possibility of organizing a pattern-matching mechanism that permits the display of the structure of quoted expressions and their actions into minute component subparts of actors involved in diabetes experiences and diabetes care in rural Sargodha.

Table 6 Methods and areas used during fieldwork

<b>Method of data collection</b>	<b>Brief description of method</b>	<b>Number/episodes and participants</b>
Daily observations	A research method, in which the researcher systematically watched, listened to, and recorded the phenomenon of interest. The researcher took part in the social phenomenon of interest by participating with respondents and observing the interactions between them and between the researcher and subjects to achieve a greater understanding.	Numerous observations of patients (within their respective families and community)
	Used in ethnographic approaches, this entails observing care seeking behavior and activities of individuals and at times participating actively.	
Visiting Public health facility (Rural Health Center <i>Chak 104 Shumali</i> )	Observing and participating in clinical encounters (such as measurements, counseling sessions and follow up checkups) in the said public health facility.	Weekly, and as suggested by the key informant to visit with scheduled follow up visits of different registered patients

Observing support treatment	Observing and participating in support treatment encounters and other activities related to support treatment i.e., <i>Chak Mangla</i> water and home based remedies	Weekly, as per the plans of the patients to visit the <i>Chak Mangla</i> and preparation of home based remedies
Observing alternate treatment	Observing and participating in alternate treatment encounters and other activities related to alternate treatment i.e., holy man and <i>hakeem</i>	Weekly, as per the plans of the patients to visit the <i>hakeem</i> and holy man (as an alternate treatment)
Case study of <i>Chak Mangla</i> water	A research method which focused on the characteristics, circumstances, and complexity of a single case, often using multiple methods. The case was viewed as being valued in its own right and whilst findings raised awareness of general issues. The aim was not to generalize the findings to other cases. Heritage and Atkinson (1984)	Three full days visit with different patients (using a water as a support treatment in their diabetes care).
Basic profile(s)	Information provided by individuals tracing their life events and how they coped with diabetes	Adherent patients: 20 Non-adherent patients: 20
Fieldwork conversations	The central goal of the said activity was the description and explication of the competence that ordinary speakers use and rely on in participating in intelligible, social interaction. At its most basic, the	Daily as situations permitted

objective was one describing the procedures by which fieldwork conversations amongst participants produce knowledge of processes that build around diabetes care.

Informal interviews	An informal chit chat during initial days of fieldwork with registered patients and key informants.	Daily, until the interview guide was finalized for in-depth interviews
In-depth interviews	The research method involved asking questions from an interview guide and tape-recording participants' replies (as per consent). This was recorded by the researcher writing down answers (especially verbatim) and summarizing the findings allowing data analysis to be conducted later.	40 In-depth interviews
Documentary evidence	Using documents to get information to complement what other methods could not provide. Non-communicable disease cards of the registered patients.	Observation of NCD cards of 71 registered patients

### 3.3. RESEARCH SITE

The current study was conducted on/in the village 104 north bound (NB) commonly known as *Chak 104 Shumali*. *Chak 104 NB* was given the title of Model Village of Punjab in 1965 by General *Musa Khan*, the then governor of West Pakistan. *Dr. Chaudhry Nasar Ullah Khan Ghuman* played a vital role in the social, economic, political and intellectual development not only of the village but of the whole area (as discussed further below in the village profile). Brigadier(r) *Saad Ullah Khan* (14 Punjab) who was recommended for *Nishan e Haider* (highest military award) and was awarded *Hilal e Jurrat* (military award for bravery) in 1971, was the brother of *Dr. Nasrullah Khan*.

This chapter also provides glimpses of the native roots, country, province and district. The information given in this was found useful during the research and also connecting the research site in the context of a larger historical and contemporary picture.

#### 3.3.1. Native Roots

Pakistan, before independence was known by its shared territory with India, and was familiar as (Indo-Pak) and subcontinent (term flourished in the age of colonization<sup>21</sup> of India). Beginnings of civilization in Pakistan started with farming village communities in Baluchistan<sup>22</sup> by the 8th millennium BCE at *Mehrgarh*<sup>23</sup>. These blossomed through the

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21 Colonization: The action or process of settling among and establishing control over the indigenous people of an area.

22 Baluchistan: Baluchistan is the land between south-western Pakistan, south-eastern Iran, and a very small section of south-western Afghanistan. (Panah) Baluchistan constitutes 44% of Pakistan's total area. (Mansoor Ahmed Baloch, 2006) It is one of the four provinces of Pakistan, and is strategically extremely important to the country because of the high concentration of natural resources including gas and oil. (Roychowdhury, 2016)

23 Mehrgarh: Mehrgarh is the site in the Kachi district, Baluchistan in Pakistan. It lies at the foot of Bolan Pass, and very much incorporated in the Indus System. The Neolithic site spans over an area of nearly 500 acres with remains only of the pre-Harappan times. Mehrgarh as a pre-Harappan site is of utmost significance in the history of the subcontinent. (Niharranjan Ray, 2000) Mehrgarh has been in the course of excavation for the past decade by the French Archaeological Mission led by J.F. Jarrige. (Ahmad Hasan Dani, 1999)

ages and emerged around 2500 BCE as the full-fledged Indus Civilization, which lasted more than a millennium.

The dramatic decline of the said civilization attracted invasions from the northwest of nomadic Aryan tribes. They were responsible for well famed Vedic civilization<sup>24</sup> (a period best known for its social stratification) that forced the cognition of the civilization to accept the ascribed castes (mainly bisected in four rigid castes). The ideology was however challenged by the Buddha<sup>25</sup> (537 BCE) and *Mahavira*<sup>26</sup> (510 BCE) but remained partially successful but attracted a reasonable number of people to follow different methods of Buddhism. The Hindu kingdoms flourished thereafter.

Western influence in Pakistan came with the *Achaemenid* Empire<sup>27</sup>, when Cyrus conquered Northern Pakistan in 558 BCE, followed by Darius adding *Makran*<sup>28</sup> and

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24 Vedic Civilization: The Vedic Age (c.1750-650 BC) began with the end of the Indus Valley Civilization, the supposed arrival of the Aryans, and the composition of the Rig Veda (Hindu sacred text). In this period, the Brahmans were scarcely known as a separate community, the caste system had not been introduced, and gods were worshipped who were subsequently superseded by deities of other names and other forms. Vedic religion seems to be polytheistic with deities such as Indra, Mitra-Varuna, Surya and Agni, however there is also evidence that these were but names of One God. (Marbaniang, 2015)

25 Buddha: Shakyamuni Buddha (Siddharta Gautama) (Baroni, 2002) was born as a prince. Siddharta abandoned his regal life and began a lifelong search for religious insight. After a period of intense meditation, he arrived at the core beliefs and practices of Buddhism, and established a community of followers and disciples, who were responsible for propagating his teachings after his death. (Baroni, 2002)

26 Mahavira: Lord Mahavir was the twenty-fourth and last Tirthankara of the Jain religion of this era. Lord Mahavir was born in 599 B.C. in the state of Bihar, India. Mahavir was a prince and was given the name Vardhaman by his parents. But at the age of thirty, he left his family and royal household, gave up his worldly possessions, and become a monk in search of a solution to eliminate pain, sorrow, and sufferings. Bhagwan Mahavir is usually depicted in a sitting or standing meditative posture with the symbol of a lion beneath him. (Shah, 2002)

27 Achaemenid Empire: The Achaemenid Empire was the earliest and the largest of the known 'world empires.' It developed around a tiny core in the modern Southern Iranian province of Fars, the modern form of the Old Persian name of the region, Parsa. "Achaemenid" derives from Achaemenes, the eponymous founder of the ruling dynasty, and was the name of the Persian royal clan (Herodotus 1.125) that ruled the empire for nearly 200 years. Its formation began from c. 550 BCE, with the conquests of Cyrus II (the Great) and Cambyses II; it was brought to an end by the conquests of Alexander the Great of Macedon, between 334 and 323 BCE. For over 200

Sindh to this Iranian Empire. The conflict between the Persians and the Greeks had its impact: Alexander of Macedon invaded Pakistan in 326 BCE, a catalyst in the process of cultural fusion of East and West in Pakistan, creating a Graeco-Buddhist culture throughout the country, with the city of *Taxila*<sup>29</sup> serving as the best example. Architecture, sculpture and the arts flourished at a sophisticated level in the *Gandhara*<sup>30</sup> culture that absorbed this and other influences.

### 3.3.2. Pakistan

Pakistan with an area of 796,095 square kilometers is bordered by Iran and Afghanistan on the west, China on the north, India on the east and the Arabian Sea on the south. The land is geographically diverse with varying climatic conditions and wide ranging

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years, it was the largest empire the world had seen, spanning from the Hellespont to northwest India, including Egypt, and extending into Central Asia up to the frontiers of modern Kazakhstan. (Susan E. Alcock, 2001)

28 Makran: One of the latest districts traversed and surveyed by the Indian frontier surveyors is Makran. Makran extends along the northern shores of the Arabian Sea between Karachi and the Persian Gulf, commencing from the Sonmiani bay on the east, and terminating somewhat indefinitely on the west within the recognized territory of Persia. Makran is a geographical rather than a political territorial designation, and may be called the most southern district of South-Western Baluchistan. (Holdich, 1896) The Makran coast has featured in the archaeological and historical records from at least as early as the third millennium B.C. (George F. Dales, 1992)

29 Taxila: The remains of Taxila are situated immediately to the east and north-east of Sarai-kala, a junction on the railway, twenty miles north-west of Rawalpindi. The valley in which they lie is well-watered by the Haro River and its tributaries, and protected by a gridle of hills-on the north and east by the snow mountains of Hazara and the Murree ridge, on the south and west by the well-known Margalla spur and other lower eminences. Arrian speaks of it as being a great and flourishing city in the time of Alexander the Great, of all the cities which lay between the Indus and the Hydaspes (Jihlam). (Marshall, A Guide to Taxila, 2013)

30 Gandhara: The region along the northern boundaries of the huge, culturally and ethnically diverse South Asian sub-continent was known in ancient times as Gandhara. It remained isolated until the beginning of 6<sup>th</sup> Century BCE, not only from the other regions of the South Asia, but also from the region beyond its northern boundaries. Around 535 BCE, the massive wall formed by the Hindu Kush and the Kara Koram mountain ranges was ultimately breached by the Persian armies under Cyrus the Great. In 438 BCE, Darius the Great extended the Persian possessions in South Asia by conquering the Taxila region east of the Indus. As a result of these conquests, a cultural union of Gandhara, west of the Indus, and Taxila, east of the Indus, came into existence, which is referred as Greater Gandhara. (Samad, 2011)



temperatures. The northern part of the country constitutes three of the highest mountain ranges: The Himalayas<sup>31</sup>, the Hindu Kush<sup>32</sup> and the Karakoram<sup>33</sup>. Another prominent physical feature is river Indus, transverse the entire length of the country and supports the country's complex irrigation system, which is the largest in the world. Arid land consists of the Thar<sup>34</sup> and *Cholistan*<sup>35</sup> deserts in Sindh and south of Punjab respectively and

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31 Himalayas: The Himalaya are the most magnificent feature on the surface of the earth. This mountain chain forms a gigantic arc stretching from the Nanga Parbat peak in the north-west to the Namche Barwa massif in the east. The Himalaya extend for a length of about 2400 kms from west to east and vary in width from 150 to 300 kms. It is made up of four distinct physical regions; the Siwalik hills, Lower Himalaya, Higher Himalaya and Trans-Himalaya. (Negi, 1990)

32 Hindu Kush: The Hindu Kush Mountains in the north-west forms part of Pakistan's border with Afghanistan. A chain of low ranges lies on Pakistan's west side. The Sulaiman and Kirthar ranges define the western extent of the province of Sindh, forming a natural border between Pakistan's land regions. The lower ranges are far more arid than those in the north, and run to the southwest across the province of Balochistan. At several points on the Hindu Kush, mountain passes cut through the tall peaks, providing gateways to invaders, refugees, fugitives and nomads. The name 'Kush,' meaning death, was probably given because these passes are dangerous. (Mohiuddin, 2007)

33 Karakoram: The Karakoram Range extend across the northern end of the country, running through Pakistan's Kashmir region. The Karakoram Mountains form one of the world's highest mountain ranges, and contain some of the most dramatic scenery in the world. This region is rightfully called the roof of the world. The Karakoram Range is part of the Himalayas that run between Pakistan and China. Many of the world's tallest mountains are found in these ranges, including K2, Pakistan's highest mountain, and world's second highest after Mount Everest. Massive glaciers rise among the mountains too. (Mohiuddin, 2007)

34 Thar: The Thar is Pakistan's largest desert region, extending over the border from India into Souteastern Sindh and parts of eastern Punjab. Sandy dunes cover most of the region. Dust storms are common in the hot months. People use irrigation to farm land near the Indus River, and draw water from underground wells. Very few people live here. (Mohiuddin, 2007)

35 Cholistan: The Cholistan is a desert covering an area of 26,000 Km<sup>2</sup> located between 27°42' and 29°45' N latitude and 69°52' and 75°24' E longitude at a height of 112 m above sea level. (I. Ali, 2009) Its old civilization has vanished mainly due to a variety of hostile invading problems caused by the Egyptian, Harappan and Mesopotamian civilizations. The prominent climatic features of the Cholistan desert are sub-tropical, arid, burning hot, monsoon rainfall with intermittent long droughts and strong summer winds having relatively low humidity and high rate of evaporation. The desert is separated into two eco-regions by old Hakra River. The northern division covers about 7,770 km<sup>2</sup> and is known as Lesser Cholistan. The purely aeolian sandy desert, called the Greater Cholistan covers 8,130 Km<sup>2</sup> in the southern region consisting of various forms of sand ridges and inter-ridges valleys. It extends about 480 km in length and 32 to 192 km in width. (Sadia Malik, 2015)

sparsely populated Baluchistan Plateau in the southwest. The country is a federation of four major provinces, Baluchistan, Khyber Pakhtunkhwa (KP) formerly known as The North West Frontier Province (NWFP), the Punjab and Sindh. In addition, there is the Federally Administered Tribal Areas (FATA), the Federally Administered Northern Areas (FANA), Azad Jammu and Kashmir (AJK) and the Islamabad Capital Territory (ICT).

Figure 1. Map of Pakistan



### 3.3.3. Punjab

The word ‘Punjab’ for the first time was mentioned in ‘*Tarikh-e-Sher Shah*’ (1580) which mentioned the construction of Fort by a fellow named ‘Sher Khan of Punjab’. Again the name is mentioned in ‘*Ain-e-Akbari*’ part 1 written by *Abul Fazal* who also mentions that the territory of Punjab was divided into two provinces of Lahore and Multan. Similarly in the second volume of ‘*Ain-e-Akbari*’ title of a chapter contains the word ‘*Punjab*’ in it.

Also the Mughal King Jahangir mentioned the word 'Punjab' in his book '*Tuzk-I Janhageeri*' (Quraishie, 1973: 183). But Archeologists have traced the signs of human habitation to times long before that of Mughals arrival. The upper basin of Indus and the Baluchistan Plateau hosted one of the earliest human civilizations known as the Indus valley civilization. The earliest signs of life human activity date as far back as 7000 B.P. The Indus valley civilization grew from small village and settlements to highly refined urban life. At its height, around 3000 B.C., it boasted the splendid cities of Harappa (Near present Day Sahiwal district in West Punjab) and *MohenjoDaro*<sup>36</sup> in the lower Indus valley. The story of the decline, whose reasons are still not completely explained, of civilization is also told through the remains of these cities.

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36 MohenjoDaro: is an archaeological site in the province of Sindh, Pakistan. Built around 2500 BCE, it was one of the largest settlements of the ancient Indus Valley civilization, and one of the world's earliest major cities, contemporaneous with the civilizations of ancient Egypt, Mesopotamia, Minoan Crete, and Norte Chico. Mohenjo-daro was abandoned in the 19th century BCE as the Indus Valley Civilization declined, and the site was not rediscovered until the 1920s. Significant excavation has since been conducted at the site of the city, which was designated an UNESCO World Heritage Site in 1980. The site is currently threatened by erosion and improper restoration.

Figure 2. Map of Punjab



The common knowledge regarding the term Punjab is as taken from two words *Punj* (five) and *Aab* (water). The land of five waters (rivers) as commonly phrased by the people of Punjab. A respondent also expressed it as:

Statement:

*Aiy punj daryavan di dharti aiy*

Translation:

This is the land of five great rivers

### 3.3.4. Sargodha

Sargodha City is located in longitude 72°-38" to 72°-43" and latitude of 32°-3" to 32°-7" and is situated at a distance of about 180 km towards north-west of Lahore. The city is

well connected to the other major cities *Faisalabad* (90 Km) and *Jhang* (126 Km), *Sheikhupura* (143 Km), *Khushab* (45 Km), *Gujrat* (210 Km) and *Sialkot* is (214 Km). The city is also connected with *Lahore*, *Faisalabad*, *Jhang* and *Rawalpindi* by rail. *Sargodha* also has cantonment board and Pakistan's largest PAF airbase. The estimated district population is 3.1 million, with 2/3rd rural and 1/3rd urban population. An average catchment population per health facility is about 160,000, with 60,800 (i.e. 38%) people aged 25 years or more.

Sargodha is a combination of 'Sar' and 'Godha'. 'Sar' is Hindi word meaning a water pond while 'Godha' was the name of Hindu *Faqeer*<sup>37</sup>. The Hindu *Faqeer* named 'Godha' used to live near a pond meant for storing of rain water for human and also animal use. The place came to be known as Sargodha after the pond and the name of Hindu *Faqeer*. Then pond which was later on filled up is now included in the area of the District Head Quarters Hospital.

Scattered settlement also existed at a distance of about half a mile towards north of the pond. The local people, the land-Owners, of this area shifted to new sites now called *Chak* No. 105 NB, *Mithamaasoom* and *Jala-l-Pur*. Sargodha town was established in 1903 in the form of planned blocks as residential quarters and civil lines area as administrative set up as well as Government servant's residences. Railway line running through the town divided the town into two parts. Blocks No. 1 to 4 of the general residential area as well as part of civil lines were constructed first. The town continued to grow on the original planned pattern in the earlier stages of growth. Only three private colonies originally called Hari Pura (now Islam Pura) developed beyond the planned town before the partition of the Indo-Pakistan Sub-Continent. The influx of refugees from across the line of partition necessitated growth at a faster rate. The town was started getting populated with few privately sponsored colonies include satellite town.

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<sup>37</sup> Hindu Fakeer: Also known as *fakir*, meaning 'poor'. Properly an indigent person, but specially 'one poor in the sight of God,' applied to a Mahomedan religious mendicant, and then loosely, to Hindu devotees and naked ascetics. (Henry Yule, *Hobson-Jobson: A Glossary of Anglo-Indian Colloquial Words And Phrases, and of Kindred Terms*, 2010)

The District headquarters were originally located at *Shahpur*<sup>38</sup> city near the left bank of River Jhelum. In the great floods of 1849 the town was washed away. In view of flood danger, the Headquarters were shifted to *Shahpur Sadar* but this site also did not serve the purpose as in the great floods of 1893 the district Headquarters got surrounded by water on all sides.

District Sargodha separated from Rawalpindi division and became the headquarters of a newly created division. The division was comprised of four districts including Sargodha, *khushab*, *Mianwali* and *Bhakkar*. However, the division was abolished by the Devolution Plan of government under the rule of General *Pervez Musharraf*<sup>39</sup> (1999-2008) with an aim to control the bureaucratic role of bureaucracy. With the following elections of 2008, the Pakistan Muslim League (N)<sup>40</sup> government came in power in Punjab province and restored the division. According to population census organization (2011), the district Sargodha consists of 06 Tehsils, 161 Union Councils and 845 villages. The literacy rate of the district is approximately 66.69%.

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38 Shahpur City is a small but historically renowned located in district Sargodha, Punjab, Pakistan. It is located near the Jhelum River, which flows 3 km away in the west. It is the old district of Sargodha region.

39 General Pervez Musharraf: President General Pervez Musharraf (born 11 August 1943) has ruled Pakistan since 12 October 1999 when he overthrew the government of Prime Minister Mian Muahammad Nawaz Sharif who tried to dismiss him and appoint another general as the army chief of staff. Musharraf hails from a lower middle-class family of Urdu-speaking parents who migrated to Pakistan from Delhi, India, when Pakistan was created in 1947 as a separate Muslim-majority state in the Indian subcontinent. In 1961, Musharraf joined the army. He received his commission in 1964 and was placed in an artillery regiment. He graduated from the Staff College, Quetta, and, later, from the Royal College of Defence Studies, United Kingdom. He became Major General on 15 January 1991 and Lieutenant General on 21 October 1995, and came into political limelight in 1999. (Ahmed, 2007)

40 PML-N: The PML-N is the largest faction of the Pakistan Muslim League, and is led by Nawaz Sharif, who has re-emerged as a political player in Pakistan in the past few months after returning from Saudi Arabia where he was exiled after being ousted from power in a 1999 coup led by Pervez Musharraf. The centrist conservative party was in power twice in the 90s, with both terms ending amid damaging allegations of corruption, despite campaigning on an anti-graft platform.

Sargodha is known for its serene orange orchards. Miles and miles of orange and guava orchards are seen along the main roadside. Field(s) of mustard leaves and golden wheat grains are observed in summers. Thick bush clusters of sugarcane and bamboo plantations are also part of the scene. A web of water canals offshoot from river Jhelum and adds to the raw beauty and agricultural fertility of this district.

Sargodha is one of the most gifted districts of Punjab in terms of its agricultural wealth. The city is also called the 'City of Eagles' as it houses the largest Airforce base and the Airforce Headquarters of Pakistan (Mushaf Air base)<sup>41</sup>. The airbase is also home to the Combat Commanders School (CCS), formerly the Fighter Leader's School. Along with rich trends of agriculture, Sargodha has much to offer, the city houses many hospitals, a cinema, shopping malls & local and a few international eateries. The most famous local dish of the town is "Jhaal Chakian Daal", a lentil cooked in organic ghee and steaming hot baked chapatti fresh from the oven which attracts people from all over Pakistan.

According to district health information system (DHIS), there are total 153 public health facilities of different level and nature of service delivery including district headquarters hospital (DHQ), tehsil headquarters hospitals (THQ), TB hospital, rural health centers (RHC), basic health units (BHU), civil dispensaries and mother and child health centers. The DHIS not just keep the track of each health facility but also grade them based on their performance including service delivery and commitment of staff. The DHIS also enlist and monitors private practitioners and their respective health facilities and also keep detailed lists of staff members in each public health facility.

The fauna and flora of the area include the *Van* (*selvadoraabeoides*), *Kari* (*salsolafostids*), *Jand* (*Prosopisspicigera*) and *Malla* (*Zigyplusnummularia*), together forming the jungle

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41 Mushaf Air Base: It is a Pakistan Air Force airbase located at Sargodha in the Punjab province of Pakistan. It is the headquarters of the PAF Central Air Command. It was known as PAF Base Sargodha until 2003, when it was renamed in honor of former Base Commander and Chief of the Air Staff Air Chief Marshal Mushaf Ali Mir, whose airplane crashed on a routine flight near Kohat the same year.

with which the uncultivated lands are generally covered. Wolves are common in the district, Jackals are numerous and can be seen everywhere (especially near the bushes crossing the pavement and roads in the evenings), and do considerable damage to the crops, especially to maize and sugarcane. Wild boar is also found in abundance and damages the crops in villages near the river. Foxes and wild cats also thrive in the area.

The existing water supply network covers 70% of the town and serves 70% of the total population. Whereas rest of the area is without it and people have their own sources of water mostly hand pumps / power pumps. According to DHIS, the water contaminations (with different pollutants).

The coverage of the sewerage facility is approximately 80% of the area. The sewer capacity is not adequate to handle the quantities of used water generated and the sewers frequently overflow. The sewerage system of Sargodha is divided into five zones. Each zone has an independent disposal station, which discharges untreated sewage to two seepage drains, one on the west side and the other on the east side of the city.

The solid waste management system (SWMS) for Sargodha is managed by Tehsil Municipal Administration (TMA). There is neither a system for temporary storage of municipal solid waste nor a proper waste disposal system, no proper landfill site is available in or out side of the city. Solid waste is dumped in open spaces and is commonly known as '*Roordhi*'. The heaps of *Roordhi* may smell distasteful (especially after the rain) and is home to straying dogs and cats.

#### **3.3.4.1. Transport**

No urban transport services are available except for pickup vans, motorcycles rickshaws and auto rickshaws. The effective capacity of the new road system is reduced by poor traffic management, poor compliance with traffic regulations and the mix of motorized and non-motorized traffic. The public transport (i.e., vans and motor-rickshaws) are found to be overcrowded (as compared to the allowed seating capacity for passengers). However, the Punjab Emergency Service Act was promulgated in 2006 to provide legal



cover to the Emergency Services Reforms initiated in 2004 from Lahore. Start of Rescue 1122<sup>42</sup> was necessitated after failure of repeated attempts to revitalize and modernize the old organizations mandated for emergency management (especially road accidents). Now as a result of the performance of Rescue 1122 during emergencies and disasters in recent years, it has also been notified as the Disaster Response Force by the Provincial Disaster Management Authority (PDMA) & Government of the Punjab. The 1122 now operates (for road accidents and emergencies) from central station university road (in Sargodha city).

### **3.3.4.2. Economics**

Sargodha is both an agricultural and industrial city. Vast fields have allowed farmers to develop a range of crops and animal breeding programs. Main crops include citrus, wheat, rice and sugar cane which are exported nationally and internationally. The main livestock includes goats, sheep, cows and buffaloes. While agricultural goods have been the main source of income for the city, manufacturing has also been growing. Main industrial activities include producing beverages, diesel engines, foundry products, glass products, leather footwear, oil mills, pesticides, insecticides, and poultry feed, plastics and readymade garments

In particular, Sargodha is known to have the largest electrical fitting manufacturing in Pakistan. 70% of the country's electrical fitting products are produced in Sargodha, which are shipped all over Pakistan. Approximately 15 large units, 200 SMEs<sup>43</sup> and 1000 cottage industry units are involved in the electrical fittings industry.

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42 Rescue 1122: The Punjab Emergency Service (Rescue 1122) is the leading emergency humanitarian service of Pakistan with infrastructure in all 36 districts of Punjab and is providing technical assistance to other provinces. Rescue 1122 has rescued millions victims of emergencies through its Emergency Ambulance, Rescue & Fire services and Community Emergency Response Teams while maintaining its average response time of 7 minutes and standards in all districts of Punjab province with an estimated population of over 100 million.

43 Small and Medium sized enterprises

Figure 3. Map of Sargodha



### 3.3.5. Chak 104 Shumali (Village 104 North/Northern Bound)

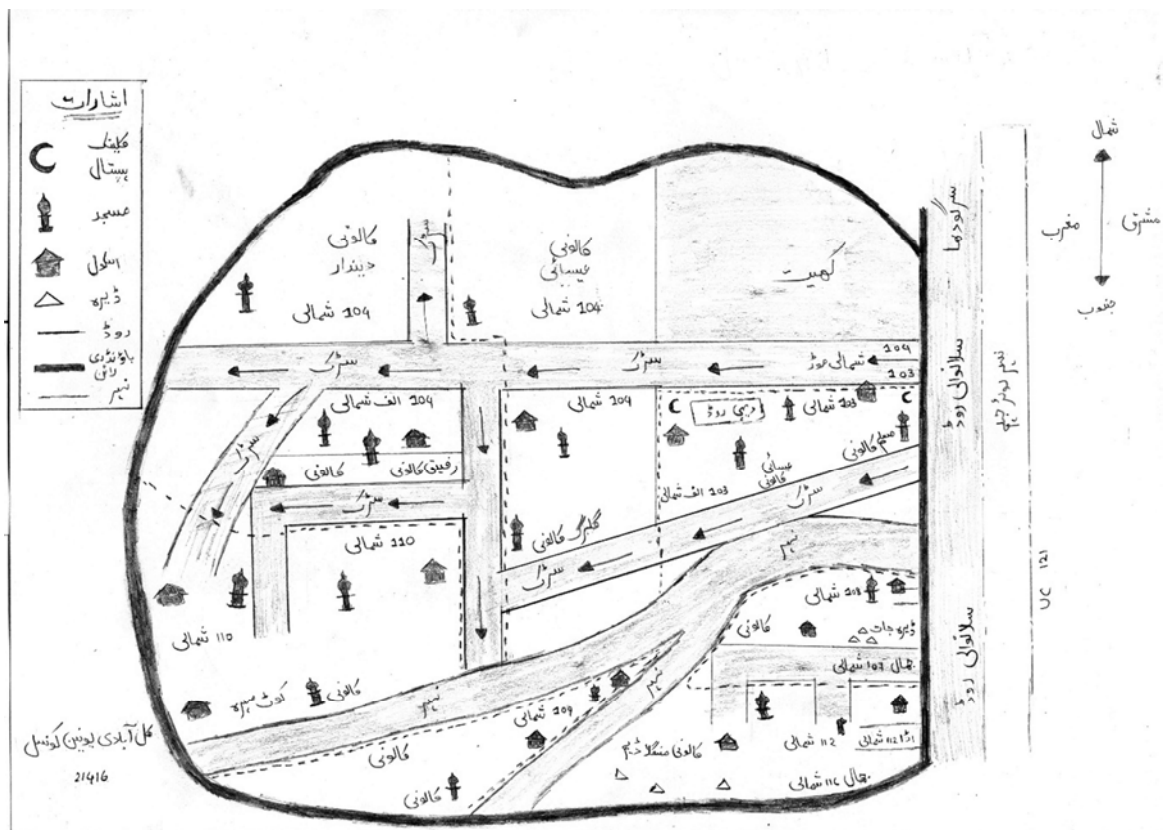
The *Sillanwali*<sup>44</sup> road connects with union council number 120 through narrow link road(s). The union council number 120 is where the administrative boundaries of *Chak*

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44 Sillanwali: The town developed in the late 19th century during the rule of the British empire. It was planned to be an agricultural business hub or *mandi* ("wholesale market"). It was a planned town developed after canals were built for agricultural purposes and a railway line was established. Even today, the railway station at Sillanwali is known as "Sillanwali Mandi" in railway records. Before the Partition of India in 1947, Sillanwali was well known for the production of cotton. Most of the population were Hindu Khatri. After partition the Hindus migrated to India and their property was taken over by the Muslim Sheikhs (having Khatri Origin), most of whom had migrated from Karnal District of Haryana state which had been part of united Punjab but became part of Indian Punjab after 1947.

104 NB starts and also connects it with *Chak* 103 NB (neighboring village) and other villages that are bisected due to stream. A water stream that goes to the *Silanwali* is 2 to 3 kilometers away from the *Chak* 104, and is also used for the water needs of the village (and adds to the land fertility). The water stream is called '85' (commonly known as *Pachaasi Jhal*).

Figure 4. Map of *Chak* 104 Shumali (Urdu)

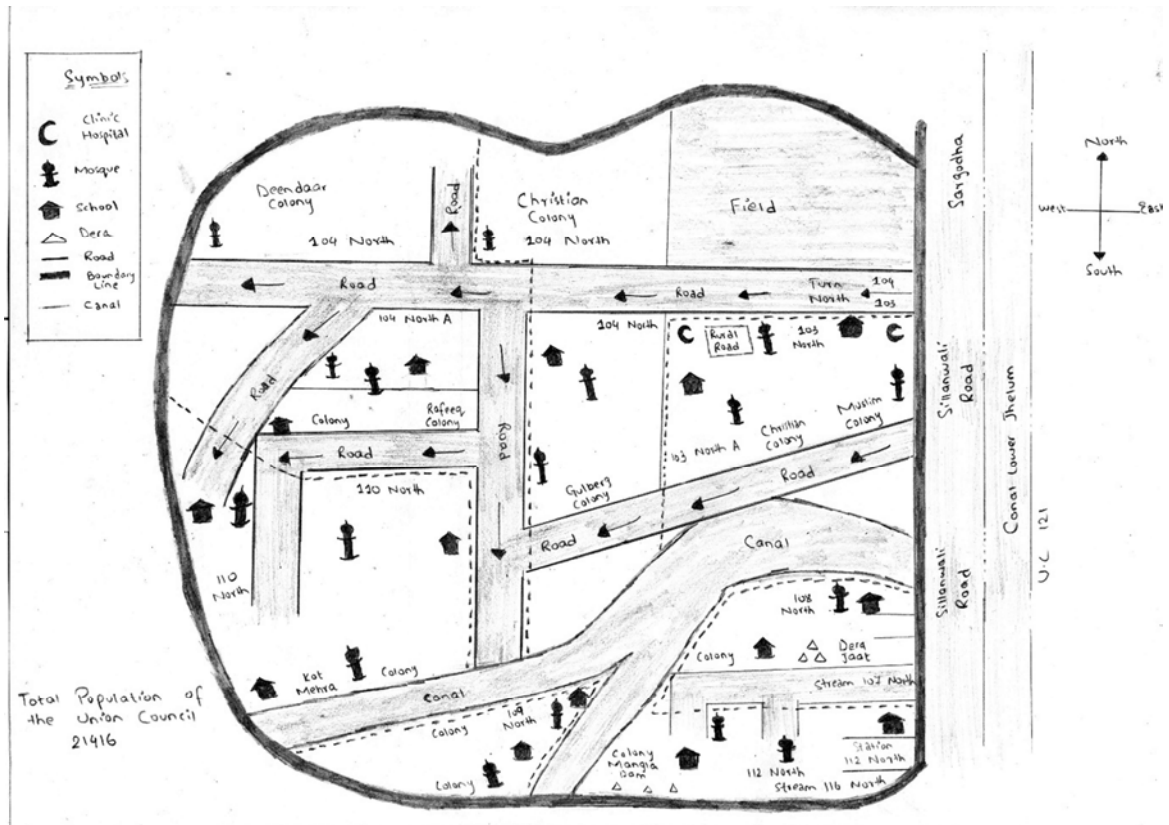


Note: The information is given in Urdu

*Chak* (village) 104 North Bound (NB) lies 10 kilo meters in the west of Sargodha city with a neighboring town called *Chak* 103 NB. *Chak* 104 NB has a rural health center, schools (both public and private) and a functional market which makes it the central village for adjoining villages. A small town with regular life of semi-urban Punjab. As per DHIS, the population of the *Chak* 104 NB is approximately more than 21 thousand.

Most of the villagers have cattle(s) including cows, buffaloes and goats. Roasters and chickens may also be found in the streets (kept by most of the people). *Chak* 104 has fertile land that brings sufficient fodder for the cattle (Khal is from wheat crops and is used for cattle food). The cattle provides the daily domestic need (of milk) and also eggs.

Figure 5. Map of *Chak* 104 *Shumali* (English)



Note: The information is given in English

The narrow road as mentioned above remains busy due to local transport (usually with motor rickshaw), mini buses and motorcycles. Every now and then one may also see a donkey cart carrying fodder, bricks and other consumables.

The narrow road as mentioned above remains busy due to local transport (usually with motor rickshaw), mini buses and motorcycles. Every now and then one may also see a donkey cart carrying fodder, bricks and other consumables. The narrow road forces at least one commuter to derail the four wheeler or similar transport (i.e., car, bus, and cart) to allow the other commuter to pass through. The motorcycle riders are also found (usually without a helmet) using the same narrow road to connect with different villages and the district.

The heat wave in summers though shrink the commute in the peak hours and one may see passengers waiting for the local transport beneath road side trees. The children can be seen (in summers) swimming in the stream that connects different villages. The police patrols (at least once) in different divided beats to stop swimming in illegal areas and also to monitor. The changing season towards winter brings fog with at times zero visibility especially early morning and in late evening.

The villagers may be found sitting even before the opening hours of the public health facility both in winters and summers. Long queues, buzzing sound, pungent smell of sweat mixed with the scents of drugs and sanitizers used in the health facility. The vehicles (both two and four wheelers) are parked within the premises of the health facility. The motor rickshaws are also found parked at the exit end of the public health facility (usually on rent basis) to transport patients.

On the other hand, early morning life brings children wearing different uniforms escorted usually by the parents or elder siblings. Same as the case with the shutdown hours of different schools that brings parents, grandparents and elder siblings to pick their respective children back to home. Villagers use motorcycles, cycles and even commute by foot to their homes from the school.

The village streets still reflects old fashioned red bricks (as if tightly knitted together). Both ends of the streets channelize drainage (usually open). The streets are flocked with children and women also talk to each other by even standing in their respective main doors.

The village is divided into different colonies connected through paved and brick roads. There is a visible difference between different colonies and accordingly different preferences including for diet, schooling, transportation and health care seeking behavior and decisions. The apparent difference in the size of the house plots and the structure of the houses does not greatly affect the harmony and cohesion within the villagers. Most of the villagers may warmly greet each other and also attend each other ceremonies and functions though they belong to different sects or even different religions at times.

### **3.3.5.1. Residents**

According to the information collected from (through informal interviews) the respondents and key informants, the settlement of the current village is even before the independence of Pakistan (14, August 1947). It was also stated that most of the settlers were originally from Sialkot (an industrial city within Punjab), and migrated in 1900s before the partition of subcontinent. An elderly male respondent shared that:

Statement:

*Saday pind wich bohtian qauman sialkoton aian san*

Translation:

Most of the castes are migrants from Sialkot, and started settling and made this village as their permanent residence

Most of the residents were found to be Punjabi speaking (with a special dialect of rural Sargodha known as *Shahpuri*). As mentioned above that the migrants were from Sialkot (a Punjabi speaking area) and were of the similar dialect. With time, the residents now hold a significant identity extracted from Sargodha and *Chak 104 Shumali*. Most of the houses, farming lands are owned by the residents of the same village.

The residents can be divided in different classes ranging from the elite class that usually steers the political setup of the village, and also bring certain development projects

ranging from agriculture to public health. The middle class ranges from the blue collar job holder, farmers to the small business owners. There is also a low income class that mostly includes daily wagers (i.e., laborers and also tenants).

The residents can also be divided in terms of their faith. The larger segment of the population are Muslims and practice the dominant sect of the Islam (discussed below). The Christian community is also visible and also considered as the functional members of the village. The Christian community not only participates in the politics (not just to secure and protect their rights) to serve the larger agenda of the village but also are engaged in different public and private jobs.

The language connects all the residents and the local dialect further strengthens the local imagery. The symbolism within is dominantly Islamic i.e., the villagers may mostly greet each other in the traditional Muslim fashion. Most of the festivals (as discussed below) are celebrated together. Both Muslims and Christians are living together in harmony and peace since the early foundation of the village.

### **3.3.5.2. General living conditions**

According to the male key informant, there are no beggars to be found in the village. The people have mixed living conditions. The colonies near the center have better living conditions along with system(s) of sanitation, electricity and basic needs as compared to the peripheral clusters. The peripheral clusters though have electricity and brick paved roads but the sanitation remain open (in small and narrow sewerage lines) outside the houses (in the streets).

Most of the houses are *Pakka*<sup>45</sup> (paved/cemented). Only a few houses were observed as *Katcha*<sup>46</sup> (unpaved/made of mud bricks) in the peripheral clusters (*Katcha* houses were

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45 Pakka: Paved, Cemented, made with bricks

46 Katcha: Unpaved, made up of mud or clay bricks

owned by the Christian community members). The affluent families (such as *Ghuman* family) have huge *havelian*<sup>47</sup> with a *baithak*<sup>48</sup> (drawing room).

The *Ghuman* Haveli especially also has a big plot in front of it next to the entrance gate. The plot is bisected as a garden and free space for parking the cars and agricultural machines. The machinery is also shared with the tenants (and other community members).

Other than the affluent families, most of the houses are less furnished and less decorated. The sitting area generally has couple of wooden chairs, *manjian*<sup>49</sup> (traditional beds), *moray*<sup>50</sup> and *piri*<sup>51</sup> (stools). The utensils used for kitchen are also of different quality when it comes to affluent families, they may offer a cup of tea and food in sensitive posh crockery as compared to others (who may mostly use stainless steel crockery).

Though the weather conditions are warm and humid, only few families and houses have the privilege of air conditioners. Most of the community members use ceiling fans and pedestal fans. The middle class families use air coolers (mostly bought from the district Sargodha). Pedestal fans are mobile and hold range of utility as to be used in the evenings when families sit in the veranda. The pedestal fan is also handy in installing quickly for guests in the guest room or outside.

Most of the houses have latrines within their homes. The children are sometimes found urinating in the open fields and also by the road side. The elders were found restricting

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47 Haveli is a traditional townhouse or mansion in India, Pakistan, Nepal and Bangladesh, usually one with historical and architectural significance. The word *haveli* is derived from Arabic *hawali*, meaning "partition" or "private space" popularized under Mughal Empire and was devoid of any architectural affiliations. Haveli (Singular) Havelian (Plural).

48 Baithak: literally means seat or place to seat, place to seat the male guests (especially in case of Punjabi Baithak).

49 Manjian: Plural for Manji (is a traditional woven bed)

50 Mooray: Plural for Moora (is a traditional stool mostly made up of cane)

51 Piri: A four legged stool (used for seat) traditionally woven.



their children to urinate in the streets. The latrines within the houses are not attached with any room or living area and is still constructed at the end of the veranda or at the one end of the corner of the house. The washing and bathing is also separated mostly from the latrines. The schools also have dedicated space for washrooms and hand washing areas. The drinking area within schools are separated from the wash areas.

The Television set can found in the upper and middle class houses. The low income groups usually gather at the local hotels (in the village center) to watch news or any important sporting event (mostly cricket match). The affluent families use dish antenna to widen the range of the TV channels. Rest of the residents use local antenna to catch state channels (mostly on current affairs, agriculture and sports).

### **3.3.5.3. Weather conditions**

*Chak 104 Shumali* bears the same weather conditions as Sargodha. It celebrates four seasons with comparatively longer span of summers and winters in contrast to autumn and spring. Summers, especially may get very hot and humid. A warm breeze also blows in summers (that makes the exposure even harder in sunlight and even under the shades of trees. The female key respondent shared that:

Statement:

*Garmian wich tay pakhay di hawa wi bari garam hondi aiy*

Translation:

Even the fan adds to the humid misery in summers

The summer season brings a strong heat wave that shapes the entire lifestyle of the village accordingly. The male members are usually found covering their face and head with a piece of cloth (even a wet cloth to avoid heat) to avoid the heat while walking and also while using bicycle and motorcycle. The attire, food preferences, drinks and even gathering hours may shift where it does not coincide with the sunlight or heat in general.

The winter season has recently started to bring smog with heavy fog leading to zero visibility and almost choking of the daily activities until the rain appears. The smog leads to cough, throat infections and skin diseases. The rapid industrial growth in Punjab at large and in Sargodha (in specific) draw heavy clouds of smog heavily in central Punjab. As soon as the smog goes away, the life come back to its routine. Warm clothes and loads of tea is served with different meals. The cold drinks consumption usually get squeezed in winters, also the food preference changes. The winter also brings certain local sweet dishes mostly cooked in the homes.

#### **3.3.5.4. Occupations**

The main occupations in *Chak* 104 NB are as followed:

18. Land owners (hold large and small plots and use it for the agriculture especially through tenants)
  - The landowner class consist of *Rajput* caste (as discussed below in detail). *Rajput(s)* claimed to be descending from royal families of the past even before entrance of Islam in India. A sense of superiority and pride is strongly observed among them. It is highly endogamous group and prefers to marry even within the same family. In a way, they prefer cousin marriages over rest of caste bonds. Going out even in the same caste for marriages especially for daughters is a source of social jeering and familial shames among them. They belong to the Kshatriya class of Hindu caste system.
19. Small business owners (mostly shop keepers including vegetable shops, fruit shops, small restaurants, small local fast food shops selling mostly oily fried foods)
  - The castes including *Arain*, and *Mekan* usually own small businesses. The *Arain* castes is usually associated with small agricultural businesses and are also considered as experts of small agricultural farming. *Mekan* on the other hand claim descent from the *Panwar (Parmar) Rajputs*, and spring from the same ancestor as the *Dhudhi* tribe. The tribe claims to have settled in the *Thal*, after the end of Arab rule in Sindh, when the Hindu

king of *Kanauj*, a *Parmar* Rajput took possession of the *Thal* region, and settled his kinsmen, the *Mekan*. The *Mekans* that settled in the *Kirana* Bar, and became pastoralist, like the other tribes of the Bar. They, occupied a territory in the *Kirana* Bar, lying to the west of *Gondal* territory, although a smaller number are also in *Jhelum* and *Gujrat* districts. Their present territory now forms part of *Sargodha*, *Khushab*, and *Mianwali* districts, although as already mentioned, there are smaller broken settlements in *Jhelum*, *Gujrat*, and *Mandi Bahauddin* districts.

20. Farmers and *Muza'ray*<sup>52</sup>

- They normally cultivate their lands as well as provide their services to work for big landlords. For their survival, they depend on big landholders of village. This group is in a kind of patron-client relationship with the big landholders. They provide their services and labor while working in their fields or other domestic chores for their patrons and in return, they get reward in shape of share from the harvest and protection from social hazards. *Mazara* is like a closed tie of his patron and depends entirely on his patron. Therefore, the patron enjoys an indispensable position for his *mazara*. During time of conflicts, these *mazaray* provide the numerical strength to their patrons.

21. Blue collar job holders (mostly working for public institutes such as post office, RHC etc.)

- The blue collar jobs are usually followed by dominantly Mughal caste but not limited to it. The Mughals claimed to be from the Central Asian Mongolic tribes that settled over a period of Mughal Empire in India. The Mughal, thus expresses limitations in agricultural skills and rely on managerial and public dealings.

22. Daily wagers (offer mostly physical labor)

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52 *Muza'ray*: Tenants and Sharecroppers; *Muzara* (Singular) *Muza'ray* (Plural)

### 3.3.5.5. Agriculture

The land is divided both for the harvest of wheat (November – April) and the plantation and maintenance of orange orchards (it remains active for six months from September till February). The orchards are also maintained in rest of the months by *Muza'ray* (Tenants and sharecroppers) for the following tasks:

1. Cleaning of water system(s)
2. Hoeing of land,
3. Maintenance of fruit trees

Cultivation is main occupation of the people. Skilled labor and professional classes such as carpenters, blacksmiths, weavers, masons and hakims (herbalist) help in the work of agriculture directly or indirectly. The farmer is known for his hardihood. He rises early in the morning, drives the cattle to fields and ploughs, weeds and work there. He takes his breakfast at nine and again goes to work in the fields and works till twelve. From twelve to three, he generally takes rest. In the evening, he returns home and takes meal and then goes to rest. The women folk in village lead a very busy life. They do household work and also work in the fields. In addition to the main crops as mentioned above, there are subsidiary crops known as *Rabi*<sup>53</sup> and *Kharif*<sup>54</sup> and *Dobari*<sup>55</sup>.

### 3.3.5.6. Education

The education (offered in *Chak* 104 NB) is mostly at schooling level. There are six schools in total further bisected as below:

There are two private schools (co-education) situated in the affluent circle of the village (near the local central market). There are four public schools in total (two schools for

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53 Rabi: Rabi crops or Rabi harvest are agricultural crops sown in winter and harvested in the spring

54 Kharif: Kharif crops or monsoon crops are domesticated plants that are cultivated and harvested in Punjab.

55 Dobari: Rotatory crop; for example sunflower is being raised on residual soil moisture in rotation with rice as a dobari crop.

boys only and two schools for girls only). All of the schools were claimed to be English medium (though the courses are taught in mostly Punjabi (mostly in public schools) and also in Urdu).

The school timings and vacations changes with the season. The summer vacations are loaded with home assignments for students up to 10<sup>th</sup> grade. The winter vacations are of a few weeks only and the assignments are shortened as compare with summer assignments. Households in proximity with/schools escort their children (usually by foot). Households in peripheral area(s) of the village drop children on motorcycle or cycle.

The private schools as mentioned above offer co-education till primary grades. The secondary education is mostly taught in separated sections/buildings. The building dedicated for secondary education (private schools) are bisected as boys and girls sections/wings.

Flocks of children wearing the school uniform (different uniform of different schools) can be found in the streets going or coming after attending their respective schools. Private schools were found to only perform/call teacher parents meeting in every few months to share the progress and inclination of the enrolled students. The school administration is recently engaged with a few public health initiatives including health education of wash and general cleanliness.

### **3.3.5.7. Castes (*Qaum*)**

*Chak* 104 NB is a home to various castes<sup>56</sup>, however the *Ghuman*<sup>57</sup> family is considered to be the most important *qaum*<sup>58</sup> and revered by the villagers. The *Ghuman* caste owns

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56 Caste: An explicitly hierarchical social system based on hereditary, endogamous groups, in which each is characterized by a specific status, occupation, mode of life, and pattern of customary interactions with other such groups. (Winthrop, 1991). Also caste is the purest type of social stratification in which mobility is severely constrained. The term Caste has been commonly used to describe any system in which the different strata are rigidly fixed (Marger, 2002: 147). In the Indian case, strata are divided not by physical distinctions between groups but by people's social descent (Beteille, 1969).

big *havelian* and lands and also have significant presence in the shape of tomb (of their deceased) in the local graveyard. The *Ghuman* are also affluent and facilitate different public and private projects of development (mostly of agriculture, microfinance and public health). The *Ghuman* family of *Chak* 104 NB claim to be the decedents from *Janjua* tribe and migrated from Sialkot before the partition of subcontinent. A key informant expressed that:

Statement:

*Ghuman tay saday waday nay*

Translation:

*Ghuman's* are the actual care takers of the villagers

The other castes included *Mughals*, *Rajput*, *Mekan*, *Kahloo*, *Arain* and also a few houses of *Maliks*. There are also occupational castes including *Nai*<sup>59</sup> (offer services as a barber and caterer) and *kasai*<sup>60</sup> (offer services as a butcher). There are also castes (of the Christian community members) mostly claiming to be from the tribes of *Jat* and *Rajput* (*Gills* and *Bhattis*).

Social status is strongly tied to caste bond because various castes in village have their own criteria of classification of other castes being equal to them or even lower in social status with that of their own. Caste based groups prefer to be operative while remaining in their caste unless there is a matter that demands them to cross the threshold of their

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57 *Ghuman*: The *Ghuman* are of both *Rajput* and *Jat* status in Pakistan. The *Ghuman* claim descent from the *Janjua*. They are found primarily in Sialkot and Gujranwala districts

58 *Qaum*: Caste is the purest type of social stratification in which mobility is severely constrained. The term Caste has been commonly used to describe any system in which the different strata are rigidly fixed (Marger, 2002: 147). In the Indian case, strata are divided not by physical distinctions between groups but by people's social descent (Beteille, 1969).

59 *Nai*: Barber, also offer services as caterer

60 *Kasai*: Butcher

own caste. These matters may include the village level dispute, a matter of contention with neighboring village, village annual fair, political issue of various tiers (like: local, provincial or national), tehsil and district level issues in agriculture, irrigation, revenue or law departments, or something that relates to police or district administration. The caste structure of village comprises Martial race<sup>61</sup>, scheduled castes<sup>62</sup>, and *Kammi*<sup>63</sup> (landless marginal and occupational groups).

The martial race(s) as also discussed above (in occupation section) are considered responsible as landowners (*Zamindar*). The land gives them the priority place in the social hierarchy of the village. In the said village, *Ghuman* family is considered to enjoy and celebrate being affluent and landowners. The martial race was found to be inclined towards investing in their upcoming generations by exposing them to modern education system (that is sending them to boarding colleges in Islamabad or Lahore).

Scheduled caste operate small businesses and are at times not considered equal to the martial race(s). The ownership and the possession of land was found to be a major indicator of social mobility though it is highly crystallized with caste based frames. The *Arain* in this case can be taken as an example of scheduled caste who are either engaged in small business ranging from agriculture to modern cottage industry, or are engaged as blue collar job holders.

The marginal groups provides its services to rest of the classes in village for their subsistence. There is a great variant of people serving in diverse occupations in village. The occupational groups include: *Nai* (barber); *Luhar* (blacksmith); *Mochi* (cobbler); *Tarkhan* (carpenters); *Gorkan* (gravedigger); *Jolaha* (weaver); *Dhobi* (washer man);

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61 Martial race: landholders, for example *Ghuman*

62 Scheduled caste: It literally means whit collars

63 *Kammi* literally means a worker, but in Punjab's socio-historical context the word has wider connotations. It's a generic term applied to all the traditional producers of specific goods and community service providers without which we could not conceive our social and cultural life till recent times. The word 'Kammi' gradually came to be associated with the artisans and artists who were considered to be of low caste or low status in a hierarchy-ridden society which looked at work with disdain. (Soofi, 2014)

*Kumhar* (pot maker); *Mirasi* (jester); *Bhaand* (comic); *Dastaango* or *Qissakhawan* (folklore teller); *Naqqaal* or *gawayyia* (singer); *Chora* (sweeper); *Chowkidar* (watchman); *Chamaar* (low caste people dealing in leather); *Qasai* (butcher); *Mistri* or *Raj* (mason); *Darzi* (tailor); *Rangsaaz* (painter); *Saees* (horseman); *Tobay* (well diggers); *Taili* (person dealing in oil trade); and, *Mussali* (servant of men's room).

### **3.3.5.8. Family and Kinship**

The village has a strong value system based on family (commonly known as *Tabbar*<sup>64</sup>). The *tabbar* is the immediate family (nuclear family) and may be considered as a social bond. Though most of the families in the village are *tabbar* like but live as extended families (a house may have more than one *tabbar*). The multiple *tabbar*(s) living under one roof may belong to the descendant of same father and mother (*paeo*<sup>65</sup> and *maa*<sup>66</sup> /*bebay*<sup>67</sup> respectively). *Tabbar* ties the off-spring to the extended family (commonly knowns as *Kunba*<sup>68</sup>/*Khandan*<sup>69</sup>) especially in case of certain cooperated tasks such as marriages, death incidents, financial emergencies and keeping *biraderi*<sup>70</sup> (brethren) and influence both inter and intra caste affairs.

It is also important to mention that the village community is male dominated and the social power and visibility increases due to number of male members within the family and kin ties. The number of sons in a *tabbar* also increases the social wealth of the father and mother. The birth of the son is taken as a birth of the *waris*<sup>71</sup> (heir) and is indeed a complex cultural position/status. The son is celebrated explicitly and the title of

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64 *Tabbar*: Family

65 *Paeo*: Father

66 *Maa*: Mother

67 *Bebay*: Mother

68 *Kunba*: clan

69 *Khandan*: Extended family, clan, from the related brethren

70 *Biraderi*: Brethren, Brotherhood

71 *Waris*: Heir, also the potential owner, custodian and care taker of the property (land).



becoming the father and mother of a *Putar*<sup>72</sup> (son) is often jubilated. It is also expressed by a number of respondents as:

Statement:

*Putar tay ghar di shaan hinda aiy tay maan da maan honda aiy*

Translation:

Son brings excellence and respect in the family and it is revered the most by mothers

The females are somehow found to grow respect with age, especially after marriage. The status of mother hood also elevates an implicit status of the women in the community at large. The menopause was found to be the definite indicator in putting women away from shame and achieving respect that is holy and divine.

### **3.3.5.9. Traditional hospitality and *Paroonachari***

The Punjab is known for its openness towards friends, brethren and society. The hospitality and *paroonachari*<sup>73</sup> is considered as the corner stone of respect and reflection of family values. The childhood friendships are well cherished, celebrated and taken great care of over the course of entire life. The friends are commonly expressed by/with different local terms having in-depth meanings such as *Yaar*<sup>74</sup>, *Beli*<sup>75</sup> and *Sajan*<sup>76</sup> by the male members of the community. The female friendships are found within the walls of

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72 Putar: It literally means ‘Son’; also considered as heir

73 Paroonachari: Guest welcoming

74 Yaar: companion/friend

75 Beli: comrade/old acquaintance/trustworthy/confidant

76 Sajan: Close friend/Soul mate

the houses. The *Sahelian*<sup>77</sup> (female friends) visit each other (mostly before the age of puberty) and play different indoor games such as *Shatapoo*<sup>78</sup> and *Guddi Gudda*<sup>79</sup>.

The guests (*paroonay*) are also given extra respect as the entire family provides the best available seating arrangements and also bed (*manja/manji tay bistra*<sup>80</sup>) to comfort and show family values. The *paroonachari* is communally endorsed and the community members respect each other in the same manner, hence providing a societal cushion and cultural respect for everyone. The guests are considered as God sent (and may be taken care of). The guests are often welcomed and greeted as:

Statement:

*gee ayan nu*

Translation:

I welcome you with all my heart

The traditional welcoming was found to change its trends due to modern products including fizzy soft drinks as an alternate to traditional sweet juices. The milk as shared

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77 Sahelian: Female friends; childhood female friends

78 Shatapoo: Shatapoo is a game where you throw a stone at a number and hop to the box where the stone lands, and is like hopscotch. A rectangle about three yards long and two yards wide is drawn. This rectangle is divided into six squares each about a foot wide. The first player stands before the starting line and tosses the stone into the first square, picks the stone and hops onwards without stepping over the box on which the stone has been tossed, and then hops back. This process is repeated for the subsequent steps. The player is declared out if the stone fails to land in the appropriate square, or the player steps on a line, or loses her balance while bending to pick up the stone, or puts her other hand or foot down, or steps into the square in which the stone has been tossed.

79 This is one of girl's popular games. Pieces of cloth are used for making dolls. Toy kitchen goods made of plastic or tin are bought at the market. Toys made up of clay, cloth or wood are sold during festive periods. Sometimes they arrange marriage for dolls. At first, they divide themselves into groups. One group acts as the boy's party, and the other group acts as the girl's party. They sing and dance, and perform all the rituals of a real marriage. (Sahay, 2013)

80 Bistra: Bed, bedding

by a respondent is more of industry based and processed that had increased its cost. Earlier the guests were welcomed with hot milk (in winters) with brown sugar and cold milk (in summers) with brown sugar. Most of the items were home cooked and also grown in certain cases. The rapid urbanization has somehow eased the detailing involved in the daily cooking and also cooking involved for guests.

An elderly female respondent shared that in her days the traditional hospitality was demanding in terms of time and physical effort. She expressed that nearly all type of food items and beverages were made at home (keeping in view the season and also type of guest).

### **3.3.5.10. Saura Paika**

The hospitality has special values for *Saura*<sup>81</sup> (in-laws) and *Paika*<sup>82</sup> (paternal family). The family ties are further created with engagements and marriages of sons and daughters (mostly within the same brethren, ethnicity and sect). The daughters when visit their *paika* (after the marriage) are welcomed with special food arrangements (especially when accompanied by her husband and children). Upon departure, the guests are often sent off with gifts and may be escorted collectively (by the host family). Same as the case with in-laws upon their arrival and departure. The female key informant expressed it as:

Statement:

*Apnay maa paeo tay apnay honday nay, wiah tu baad paikay wich dhian vee  
parhonian ho jandian nay*

Translation:

Daughters can never be an outsider for their parents but after marriage a daughter comes to her parent's house as a guest

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81 Saura: Also known as Sauray which means in-laws

82 Paika: Paternal family (especially used for married daughters)

It is a normal practice that daughters (*dhian*<sup>83</sup>) are told from an early age to remain flexible so that they may adapt the household culture of their in-laws (*sauray*). It was emotionally expressed by a female respondent that:

*Statement:*

*Sauray maa paeo tu wadh ho janday nay, sad jeena marna aithay he aiy*

Translation:

Parent-in-laws become equal parents and this house becomes the actual house of the daughter

### **3.3.5.11. Religion**

The locale is home to both Muslims and Non-Muslims (Christians). The Muslim community is further divided as *Sunni*<sup>84</sup> (majority) and *Shia*<sup>85</sup> (minority). The *Sunni* community members are further from two major schools of thought (*Barelvi*<sup>86</sup> and

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83 Dhian: Daughters

84 Sunni: A Sunni is a person who strives to live and act according to customs and traditions. The substance of the customs consists of the sayings and teachings that were passed down from Prophet Muhammad (PBUH). (Smith, 2010) The sect was born as a political faction, soon after the death of Islam's founder, Prophet Muhammed (PBUH). The Sunnis believed in choosing Mohammed's successor through the consensus of the majority of believers. (Haqqani, 2006) The Sunni majority spoke out for the selection of the caliph from the Quraysh tribe, the Meccan 'nobility'. Abu Bakr emerged as a victor from the rivalries that broke out after Muhammad's death. (Smith, 2010) The Sunnis founded the Khilafa (Caliphate) which changed hands many times and ended only in 1924 with the fall of Turkish Ottoman Empire. (Haqqani, 2006)

85 Shia: The sect was born as a political faction, soon after the death of Islam's founder, Prophet Muhammed. According to the Shi'a, the "party (shi'a) of Ali", Muhammad was on the way to Madina when at the pond of Khumm, he appointed Ali to be his successor. As the Shi'i later taught, the blood descendants of Muhammad inherited his prophetic charisma, and thus, were currently called upon to lead the community. The Twelver Shi'as are by far the largest Shi'a sect. The name 'Twelver' refers to the series of twelve leaders (Imams) from the family of Prophet Muhammad, who according to the beliefs of adherents of this domination were appointed by God. (Smith, 2010)

86 Barelvi: The Barelvi is a revivalist movement created by Imam Ahmed Raza Khan Barelvi in the late 1800s, which played a decisive role in the renewal of Islam in modern India. (Cesari,

*Deobandi*<sup>87</sup>) but live as a mixed community. The Christian community members live in a separate cluster (mostly in the periphery of the village). A few of the male respondents shared (during the informal interviews) that:

Statement:

*Asi pind wich ral mil kay rehney aan tay ik dojay da khayal rakhi da aiy*

Translation:

We live together in this village as a family and we take care of each other

There is no incidence of religious violence within different sects (of Islam) or within different religions present in the community as mentioned above. Most of the religious gatherings in Ramadan, Muharram and Christmas are mutually respected and even participated by the notables and commoners of the village.

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2013) The name Barelvi comes from the native town of Ahmed Raza Khan of Bareilly in North India. Often, they prefer to be known by the title, the Ahle Sunnat wa al- Jamaat (the People of the Sunnah and the Authentic Community). This name implies their self-perception of being part of an international majority movement within Sunni Islam grounded within the ongoing tradition. They permit praiseworthy innovations within Islam, following the majority position, provided that they are in keeping with the Qur'an and Sunna. They embrace Sufi etiquette and practice, are the traditional custodians of the shrines of the Friends of God (*awliya*) in the Subcontinent, and have developed an understanding of the intercession, both of Muhammad and the *awliya*. (C. T. R. Hewer, 2006)

<sup>87</sup> Deobandi: The answer of the founders of the Deobandi Movement, Muhammad Qasim Nanutavi and Rashid Ahmad Gangohi, lay in education. They founded a centre of Islamic Studies in the town of Deoband in Saharanpur District. From this base, they established a chain of madrasas (schools) throughout India and wherever their followers migrated around the world. The principles that underlay this movement were a turn to the purity of the Qur'an and Hadith as the two main principle sources of Islam, and an avoidance of elements associated with Hindus or British values. They emphasized the importance of the Hanafi School of Sunni Shari'a, and avoided anything that might be drawn from Shi'a practices. A restricted form of Sufi practice was permitted, but there was to be no intercession of pirs. (C. T. R. Hewer, 2006)

### 3.3.5.12. Places of Worship

*Chak* 104 NB houses a Church for the Christian community. It also has an *Imam Bargah*<sup>88</sup> in the neighboring catchment area (*Chak* 103 NB) for the *Shia* community members. There is also a grand mosque (for the *Sunni* community members). Both key informants expressed regarding the peace and harmony within different sects of Islam and also with the Christians.

The places of worship are managed by their worshippers in a way where each religious community has nominated a group of trustworthy committee members (only male members). The management includes the funds, maintenance of the building and keeping harmony with the other faiths in the community.

The community members' visit to their respective places of worship for certain reasons including prayers and also spiritual healing. The Christian community arrange special prayers for the ill and sick in the village. The space around the church was arranged with seating arrangements to attend the spiritual prayers. Such prayers were found to be open for all the villagers regardless of their faith. Most of the places of worship usually arrange collective prayers as social cohesion and harmony in case of emergencies or any social problem.

### 3.3.5.13. Food and diet patterns

Most of the people eat at their respective homes (as explained by most of the respondents and also by the key informants). It is also found that the beef consumption is high in the village. *Chak* 104 NB is also a meat provider for other adjoining small villages. Other than Tuesday and Wednesday, meat is sold every day and butchers are sold out by the evening every day.

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<sup>88</sup> Imam-bargah: Also known as 'Imambaara', it is a hybrid word *Imām - bārā*, in which the last part is the Hindī *bārā*, 'an enclosure'. It is applied to a building maintained by Shī'a communities in India, for the expression and celebration of their religious ceremonies and rituals e.g. majalis and milads.

The community members are fond of eating traditional food cooked in oil and desi ghee<sup>89</sup> (though this trend of using desi ghee is declining with modernization). The concept of bakery products are also emerging in the villagers along with variety of soft drinks and packed juices.

There are two major local eateries (known as *dhabba*<sup>90</sup> that offer curries in their menu made up of lentils (daily), vegetables (daily) and meat (mostly beef and chicken – thrice a week). There is also a grand *tandoor* (cylindrical clay oven) that offer *chapatti* (daily), *khatai*<sup>91</sup> (weekly) and *Naan*<sup>92</sup> (on special request). There are also seven permanent daily stalls for local fast food (that offer *samosa*, *pakora*<sup>93</sup>, *jalebi*<sup>94</sup>, and *namak-para*<sup>95</sup>).

Water melon, sugarcane juice and sweet lemonade are the most sold items in summers. On the other hand *pakora*, *samosa* and oranges are commonly observed in winters as per general observation(s). The male key informant shared that both oily and sugary items are well consumed by the community members. The sugar, oil and meat intake was observed

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89 Desi ghee: Boiled butter; the universal medium of cookery throughout South Asia. In general, ghee is prepared by four methods, namely, desi, creamery butter, direct cream and pre-stratification methods. The desi method consists of churning curdled whole milk (dahi) with an indigenous corrugated wooden beater, separating the butter, and clarifying it into ghee by direct open pan heating. (N.C. Ganguli, 1973)

90 Dhaba: Dhabas (as plural for Dhaba) are small local restaurants and or also truck shops which are usually located along the highways. Dhabas generally serve delicious, heavily spiced dishes preferred by many travellers. (Nayak, 2011) The standard drink is chai. (Bruce Kraig, 2013)

91 Khatai: Also known as Nankhatai are shortbread biscuits popular in India and Pakistan. The word Nankhatai is derived from Persian word Naan meaning bread and "Khatai" from an Afghan word meaning Biscuit.

92 Naan: Bread, also baked bread baked in cylindrical oven (known as tandoor).

93 Pakora: Pakora, also known as a fritter, is a savoury deep-fried cake, containing bits of cauliflower, eggplant, or other vegetables. (Cauz, Encyclopædia Britannica, 2010)

94 Jalebi: A rich sweetmeat made of sugar and ghee, with a little flour, melted and trickled into a pan, so as to form a kind of interlaced work, when baked. (Henry Yule, Hobson-Jobson: A Glossary of Anglo-Indian Colloquial Words And Phrases, and of Kindred Terms, 2010)

95 Namak-para: Namak-para is a salty ribbon-like strip of pastry, delicately seasoned with ajwain, cumin seeds, carom seeds, and caraway seeds and deep fried in pure ghee.

as generally inclined towards high ratio (throughout the year) as compared to fruits (except mango and oranges) and vegetables. The lentils are also part of the most of the home menus.

The Holy months of *Ramadan*<sup>96</sup> and *Muharram*<sup>97</sup> (first ten days of it) does affect the routine eating patterns. Both of the key informants shared that the food consumption increases in the above mentioned holy months. It was also observed and found that both sugary (especially drinks) and oily food items (*langar*<sup>98</sup> and *niaz*<sup>99</sup>) are consumed more in the said months as compared to the routine intake.

### **3.3.5.14. Local transportation**

The most common transportation as observed was motor-rickshaw (maximum two persons accompanying children) and van (mostly used as 15 to 16 seater vehicle). Motorbikes are also common in use (most of the riders were observed not wearing helmet for safety purpose). Only a few affluent families have cars (mostly used to travel to cities such as Lahore and Islamabad).

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96 Ramadan: It is the ninth month of the Islamic Calendar, in which the Muslims are obligated to observe fasts throughout the month. The month of Ramadan also marks the dates of Shab-e-Qadr, or the Night of Value, during the last ten days. Ramadan, the ninth month of the Islamic lunar calendar, is a holy time in the Muslim world. For all observant Muslims it is a full month of fasting in commemoration of the first verses of the Qur'an being passed down from heaven to the Prophet Muhammad. The Qur'an quite plainly states the historical, spiritual and didactic reasons for requiring the fast in verses 2:183-5. 'O you who believe! Fasting is prescribed to you as it was to those before you, that you may learn self-restraint. Ramadan is the (month) in which was sent down the Qur'an, so every one of you who is present (at his home) during that month should spend it in fasting.' (Sandıkçı & Rice, 2011).

97 Muharram: It is the first month of the Islamic calendar. It is one of the four sacred months of the year. It is held to be the holiest month, Ramadan coming after. The word "Muharram" means "forbidden". Since the Islamic calendar is a lunar calendar, Muharram moves from year to year when compared with the Gregorian calendar.

98 Langar: It is the charitable distribution of eatables and community meal, mainly at the sufi shrines, organized for the poor and the visitors. It is also distributed on important Islamic days and during the mourning days in Muharram.

99 Niaz: Blessed food distributed among the devotees in religious ceremonies and rituals.



There are few pickup vans used for the transportation of fresh vegetables, fruits and other grocery items. The vans not just transport edible or grocery based items but also other appliances. Same pickup vans are used/hired in case of emergency (especially in case of delivery) to be transported to the district level health facilities. Most of the patients (in case of emergency) are transported by installing a *manji* (small bed). The patient is often escorted by family members (both male and female).

Other than mechanical vehicles, donkey carts are also used by marginal groups in the said village. The carts are used to transport agricultural items, bricks, fodder for cattle etc. The donkeys are often parked along the carts in tree shadows (especially in summers). A piece of cloth was often found placed on the back on the donkey (in winters) to protect it from mist and fog.

### **3.3.5.15. Local festivals**

*Visakh Mela*<sup>100</sup> (wheat harvesting festival) is an annual carnival. Farmers sow the wheat in the months of October and November as in winter season temperature conditions are best for its growth and the months of April and May the temperature is suitable for its ripening. Then in May and June, harvesting, threshing and winnowing of the grains starts.

On the other hand *Eid Milad un Nabi*<sup>101</sup> (Jaloos<sup>102</sup>) is also an annual religious (Islamic) gathering. *Eid Milad-un-Nabi*, also known as the Prophet Muhammad's birthday, is a

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100 Visakh Mela: wheat harvesting festival

101 Eid Milad-un-Nabi: 12 Rabi' al-awwal is the accepted date among most of the Sunni scholars, while Shi'a scholars regard 17 Rabi' al-awwal as the accepted date. Muslims celebrate Eid Milad-un-Nabi, the anniversary of the birth of the Prophet Muhammad, because he is their beloved Prophet, the recipient of the Holy Quran. The extent of the festivities of this day is restricted, since it also marks the anniversary of the Prophet's death. Prayers are offered in mosques, and scholars recount events that emphasize the Prophet's noble character. Songs are recited in his praise, as well as poetic verses from the Quran. Charitable donations are made freely and generously. Friends get together to have sumptuous meals, and food is served to the poor, and also distributed amongst guests visiting the shrines. (Moon, 2015)

102 Jaloos: Religious procession enacted during holy months in Islamic calendar including Muharram and Rabi al-awwal.

public holiday in Pakistan. *Sunni* Muslims observe *Milad-un-Nabi* on 12 *Rabi-ul-Awwal* (third month of the Islamic calendar) while *Shia* Muslims observe it on 17 *Rabi-ul-Awwal*, coinciding with the birthdate of their sixth *Imam Jafar-al-Sadiq*. *Chak* 104 *Shumali* becomes the central village for the neighboring communities to participate in the jaloos (of *Eid Mild e Nabi*). The *langar* and *niaz* (community kitchens) are arranged and served for all the adjoining villages (*chaks*).

The key informants shared that the *Bahaar-Aai*<sup>103</sup> is also a cultural event where the *Mirasi*<sup>104</sup> biradri do a walk with flowers of spring and distribute flowers among local people and get money from them (in return). The flowers are usually given to the affluent families by reaching their respective places. The flowers are distributed along with few locally written songs (that are sung with the sir names of the affluent families). The affluent family members give money. This ceremony may last for an hour or even two hours.

### **3.3.5.16. Religious events**

Both *Eid ul Azha*<sup>105</sup> and *Eid ul Fitr*<sup>106</sup> are celebrated by Muslims. *Eid ul Fitr* calls for the consumption and also distribution of sweet dishes including *halwa*, milk vermicelli, and

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103 Bahaar-Aai: Coming of Spring, Celebration of Spring season

104 Mirasi: The term Mirasi derives from *miras*, simply meaning lineage. (Saeed, 2001) They are bards, impersonators, genealogists, singers, dancers and storytellers like the Bhat in the Punjab, Pakistan and northwest India. The Mirasi specialize as *bhand*, or comedians. Teams of Mirasi musicians and singers perform songs of romantic love. (Philips, 2001) A Mirasi is a sort of low-class minstrel whose women dance and sing, but only it is said in the shelter of the zenana, and in the presence of the other women. The Mirasi attends weddings and funerals, where he recites the genealogies of the wedding pair or describe the brave acts of the dead man's ancestors. (Crooke, 1907)

105 Eid-al-Azha: Also known and pronounced as Eid al-Adha ("Festival of Sacrifice") is the second of the two great Muslim festivals, the other being Eid al-Fitr. Eid al-Adha marks the culmination of the hajj (pilgrimage) rites at Minā, Saudi Arabia, near Mecca, but is celebrated by Muslims throughout the world. It begins on the 10th of Dhu'l-Hijja, the last month of the Islamic calendar, and continues for an additional three days. During the festival, families that can afford to sacrifice a ritually acceptable animal (sheep, goat, camel, or cow) do so, and then divide the flesh equally among themselves, the poor, and friends and neighbours. Eid al-Adha is also a time

*paneeri*<sup>107</sup>. This Eid is also known as sweet *Eid* and having sweet dish is considered as a Sunnah of Prophet Muhammad (PBUH) before going to the collective prayer of *Eid*. Most of the sweet dishes (as mentioned above) were mostly prepared at home. Male members bring required materials from the nearby market(s). Most of the sweet dishes were made out of Milk. The milk was ordered even a few day before the arrival of Eid. The Milk was boiled in metal pots in nearly all of the houses. The sugar (white) was added along with dry fruits and other items. The sweet dishes were left over night to cool down naturally and were covered with linen or cotton clothes. The sweet dishes were shared not with the family members but also visiting guests and neighbors.

*Eid ul Azha* brings beef and mutton (it is consumed and distributed as well). This *Eid* brings festivity and economic activities for few classes. The sheep, goats, cows and camels are sold and bought by individual customers or seven parties together (in case of camel or cow). The cow and camel are slaughtered as seven parts shared by seven persons. Each part holder were distributed responsibility including safety, cleanliness, feeding, slaughtering and distribution of meat equally in seven parts. The meat is distributed among family, poor and neighbors. The meat is also cooked in the three days of the *Eid*. The above mentioned animals are slaughtered on all days of *Eid* (keeping in view the availability of the butcher). Most of the animals are slaughtered at home (in the veranda) or at community level spaces (i.e., open space next to the mosque).

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for visiting with friends and family and for exchanging gifts. This festival commemorates the ransom with a ram of the biblical patriarch, Ibrahim's son Ismail, rather than Isaac, in Judeo-Christian tradition. (Cauz, Encyclopædia Britannica, 2010)

106 Eid-al-Fitr: It is the first of two canonical festivals of Islam. Eid al-Fitr marks the end of Ramadan, the Muslim holy month of fasting, and is celebrated during the first three days of Shawwal, the 10th month of the Islamic calendar. There is a performance of the communal prayer (*ṣalāt*) at daybreak on its first day. Eid al-Fitr is a time of official receptions and private visits, when friends greet one another, presents are given, new clothes are worn, and the graves of relatives are visited. (Cauz, Encyclopædia Britannica, 2010)

107 Paneeri: Paneeri is a traditional form of cheese seasoned with dry nuts, which is produced from sour milk. *Paneer* is marble white in appearance, having firm, cohesive and spongy body with a close-knit texture and a sweetish-acidic-nutty flavor. (Kumar, Rai, Niranjan, & Bhat, 2011)

The Muharram processions are organized jointly by both Shia and Sunni community members of *Chak* 104 and 103 NB (*sabeel* is arranged on most of the streets in the first 10 days of Muharram in the said villages). The Christian community members also celebrate Christmas on 25<sup>th</sup> of December every year. The Muslim community members also participate in the Christmas gatherings. Recently a cake is cut as a ceremony on Christmas after the morning prayers in the Church. The cake was found to be distributed among the attendants of the ceremony (both Christian and Muslims).

Annual gathering of *Baba*<sup>108</sup> *Jhalay Shah*<sup>109</sup> is observed annually and attract plenty of visitors from both *Chak* 104 and 103 NB. A female respondent shared that:

Statement:

*Baba gee day darbar tay bari shifa aiy, mein tay har maheenay hazri deni aan*

Translation:

This shrine offer health and healing to us. I visit this shrine every month

The custodian of the shrine of the above mentioned was found to arrange food for the people who attend the annual gathering. The gathering was arranged for three consecutive days. The attendants of the gathering also bring home cooked food to distribute as a humble gift to the followers and attendants of the gathering. Distribution of home cooked food is considered as a blessing and may bring spiritual healing to unknown illnesses and sicknesses.

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108 Baba: The word 'baba' is highly respectful title for an enlightened, pious, irradiated person who sacrificed his personal gain and loss notion over non-material objects that are God, manhood, self-purification, etc.. This word generally denotes age, knowledge, righteousness of a person. It is also commonly used as a term of address for old men.

109 Jhalay Shah: The name of the Muslim saint who lived his life in simplicity.

### **3.3.5.17. Market(s)**

There is one main market in *Chak* 104 NB. This market also serves as the main market for adjoining small villages. The market has a small restaurant and few stalls along with small general stores for local grocery. The market also has vegetable and fruit shops as well. The changing trend in the consumption towards different edible items, appliances, semi-finished and finished products paving a way to flourish this market. The washing detergents for example have taken place instead of the traditional washing soaps.

The market also has a shop that offer services to fix general electric appliances including televisions, radio transmitters, video cassette recorder players, audio cassette players, light bulb holders etc. The neighboring shops of the above mentioned shop are mix of a few general stores that sell daily routine items including cooking oil, ghee, tea, sugar, rice, flour, lentils, stationary, local brands of chocolates, local brands of biscuits, local brands of toffees and chewing gums etc. The general stores also have a dedicated space for the refrigerator to display and refrigerate soft drinks including local brands of juices, fizzy drinks. The stores also have mineral water and pack milk. A general has also started selling the diapers, earlier the diapers were to be found in tehsil or district level pharmacy and general stores. The said market however has no pharmacy, the only pharmacy is with the rural health center.

The market also have a few restaurants and food stalls. The restaurants not only sell cooked gravy food items but also deep fried items in the oil. The food stalls menu was found to be rather monotonous as compared to the restaurants that offer different food combination. The food stalls offer oily foods both salty and sweet and may be considered as traditional fast food. The restaurants are not heavily invested in terms of their respective structures and outlook. The market also has a shop that offer catering services and also provide seating arrangements and tents (for limited gatherings).

The market is almost accessible from all sides of the village. The main mosque can also be found on walking distance from the market. A public school may also be food facing towards the main mosque. The market becomes busy in the morning working hours and

goes to the peak with closing hours of the school. The villagers shop on daily basis, weekly and monthly basis as well. The fruits and vegetables are usually bought daily whereas, meat is bought once or maximum twice a week. The major household related grocery is procured once in a month, the first week of every month brings this exercise for the middle class. The affluent families however rely less on this market and get most of the things from the District Sargodha.

Most of the shopkeepers (also the residents of the same village) use tarpaulin type cloth hanged from the height and tilted with bamboos in front of the shop (on the head of the entrance gate) to avoid heat wave in summers and also rain (especially in winters). The shops are elevated enough to protect itself from the heavy rain water. The grocery items can be found placed on the wooden and also cemented shelves.

The market remain busy till late evening, however the busy time fluctuates with the season. Male members of the community can be found sitting and discussing different issues in a friendly manner. The mosque, schools, shops and restaurants makes the market as a village center comprising of different economic, social and religious activities.

### **3.3.5.18. Attire (general apparel/outlook)**

Most of the villagers (both male and female) wear the traditional *shalwar-kameez*<sup>110</sup> (subtle colors). It was also observed that the male community members wear (*Boski*<sup>111</sup> & *Latha*<sup>112</sup>) on special occasions such as *Eid*, Wedding ceremonies and important cultural gatherings.

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110 Shalwar Kameez: A long top with a pair of loose trousers, traditionally worn in the Sub-continent. It is also the national dress of Pakistan, mostly common in the Punjab.

111 Boosky: boosky is an off-white, silk fabric

112 Latha: a white, cotton fabric

Elderly men wear dhoti<sup>113</sup> with *kameez* (shirt) instead of *shalwar* (trouser). A few of the elderly female were also observed wearing dhoti (especially in summers). Youngsters have started wearing jeans and shirts (only for occasions) but regularly wear *shalwar kameez*.

Men usually wear *peshawari chapal*<sup>114</sup>. Ladies wear sandals and slippers. Men also wear shoes in winters, whereas *Muza'ray* wear rubber boots while working on/in the fields. It was also observed that a few people walk bare foot (and don't feel any discomfort in it).

The village also have two shops that offer services as tailor of *shalwar-kameez*, whereas the villagers buy clothes (for stitching) from the nearby tehsil and district. The religious and marriage ceremonies though bring colors but still with modesty. The male members prefer wearing a jacket/coat in winters over *shalwar-kameez*. Same trend changes with a waist coat in summers. Women on the other hand in most cases stitch and tailor the clothes within house or may also outsource to someone who lives nearby and offer such services. Girls wear bangles of different colors along with bright color clothes (especially on weddings and *Eids*). The lads have started wearing a jeans and shirt on special occasions to stand out. Boys also like to wear joggers with jeans and try to experiment western style in recent cases.

A beauty parlor can also be found in the central colony run by a resident (who completed the course of beautician from Sargodha city). The parlor offer services of beautifying the bride. It was shared that the bride still prioritizes the traditional red color as a bride dress. Men on the other hand were found to receive services from the local hair dressers. The local hair dress shops offer services to beautify the groom by arranging facial cleaning etc.

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113 Dhoti: A traditional dress locally worn by peasants, farmers, and also a few landlords in the villages of Pakistan, specifically the Punjab. It is an unstitched piece of cloth, tied around the waistline.

114 Peshawari Chappal: Peshawari Chappal is a type of sandal, made from a separate insole, sole and heel, two vamps, two quarters and one back strap, and is fitted with buckles for fastening. (Research, 1950, 1951)

### 3.3.5.19. Leisure activities for locals

*Asar*<sup>115</sup> (early evening) – *Maghrib*<sup>116</sup> (sunset) is considered leisure time. Young men play cricket and volley ball (not religiously though). Every *biradari* (caste and ethnic based brotherhood) has a get together point where they sit and discuss certain socio-political issues on the said time as mentioned above.

People usually go to bed around 9 PM in winters and maximum by 10 PM in summers. Everyone wakes up with *fajar*<sup>117</sup> *aqaan*<sup>118</sup> (morning call of prayers). Sleeping late (after the sun is up) is considered un-holy (*nahoosat*<sup>119</sup>). Local perception is the earlier you wake up, the more successful you are (because according to local understanding, God's blessings are distributed in the morning). Women usually stay indoors and do house chores (most of them start working early morning). Women also gather within their respective courtyards or at times in the courtyard of any extended family member in the evenings. The gathering is often supervised by the eldest female.

Since there isn't any park in the village, men would still spend time around the fields (especially in the empty fields where children can play). Women on the other gather in the street or go to each other's houses. Girls also go to each other's house (after taking

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115 *Asar*: the third prayer, that comes in the afternoon and after the *Zuhr* prayers. In the afternoon or midway between noon and sunset, when the worldly involvements are at a peak, the third prayer of four units befalls the believer (Sayeed & Prakash, 2013).

116 *Maghrib*: the fourth prayer comprising of three units, which is offered immediately after the sunset, in the twilight. The fourth prayer is offered in three units soon after the sunset when the day has folded successfully. It is time to express gratitude to Allah for a well ended day and seek his forgiveness for all sins (Sayeed & Prakash, 2013).

117 *Fajar*: The first prayer of the day is at dawn before sunrise comprising of two units. (Sayeed & Prakash, 2013).

118 *Aqaan*: the call to prayers; *Aqaan* is recited five times a day, summoning people to offer their daily prayers; "Pray as you have seen me praying and when it is the time for the prayer one of you should pronounce the *Adhan* and the oldest of you should lead the prayer". (Sahih Bukhari-Book 11: Call to prayers; Hadith 604) (Sayeed & Prakash, 2013).

119 *Nahoosat*: Unholy, evil, bad omen



permission from their respective mothers or grandmothers) and play for hours within the premises.

### **3.3.5.20. Local games/physical activities**

Cricket & volley ball are the only two games that young adults (and middle age) indulge into (especially in the evenings). There are no parks or gym in the village. People walk (relaxed walk) on the side-walks of the roads and also by the stream (mostly male members).

The volley ball net was found to be installed around late afternoon in most days of the week. The children and young lads were found to play until the serious players arrive. The teams were found to be not loosely divided and the competition was taken healthily and the matches may go for few weeks. Friday evening brings audience to the volley ball where elder males were to sit all around the marked area (boundary lines of the volley ball court). The boundary lines of the volley ball were maintained by young boys who fresh it up after every two sets with white chalk. Same empty ground was found busy with cricket where both children and lads play cricket (mostly loosely distributed teams) with easy and customized rules and regulations. No boundary line was found to be drawn (and every now and then a small friendly quarrel may appear on umpire's decision). The cricket bats were found to be bought from a nearby Tehsil *Sillanwali* (famous for wood craft) and the tennis balls are used with electric tape rolled over it (to increase the volume and grip).

Elders were found sitting on the grass and dust for the entire evening. The elders keep on talking with their peers and may also cheer the teams and young boys and may also suggest/guide changes or may instruct/advise in case of a dispute over a decision. The decision of the elders in any case was found to be considered as full ad final and may be happily received by both teams/parties.

The children were found playing (local games) in the streets (especially in the evenings) including *bantay*<sup>120</sup>, *gulli danda* and *lukan mitti* (hide and seek). The children are often monitored by their respective mothers and elder siblings (off and on).

The *bantay* were observed being sold on the local shops (kept in a jar). The *gulli danda*<sup>121</sup> on the other hand is made by the children themselves by using wood planks (usually carved with the help of stones and knife). The games were found to be played with a serious competition that may at times lead to a quarrel or dispute usually ease away by the elder women or mothers. The *bantay* are played both individually and in terms of distributing team members. A pit hole was found to be made by both teams and marbles are shot to gain score. It was observed that the marbles of the losing team were found to be the winning price for the winning team. A good looking clear marble was considered valuable for the children and in that case most of the competition revolve around a few marbles.

The *gulli danda* was found to be played in bigger space and was found to be enjoyed the most when played in two teams. Children were found to wait for the person who owns and possess the wooden planks and the game finishes as soon he leaves the arena. The hide and seek was also found to be played both individually and in shape of making teams. Hide and seek also include female team members.

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120 Bantay: or Marbles; also known as Kenchay or Kanchay, is a traditional game locally played by the children in rural areas of Pakistan. A pit is made to score the bantay in it and is usually played by two players or two teams comprising of two members each.

121 Gulli Danda: a locally played sport, mostly in the rural areas of Pakistan. It consists of two sticks, longer one being the *Danda*, while the shorter one being *Gulli*. The name stems from the two sticks that are the only real equipment. The *gulli* is about five inches long, and the *danda* is about two feet long. Both are cut from the same length of wood and should be about an inch in diameter. The shorter *gulli* is then sharpened to a dull point at each end, while the *danda* is pointed at only one end. The game is played in an open field and can be played by two equal-numbered teams (normally not to exceed seven per team) or two individuals. It is played in India, Pakistan, and Sri Lanka, with only slight variations, and also goes by the names of *gilli danda* or *danda guli* in the two former countries, while known primarily as *gudu* in Sri Lanka (Craig, 2002).

### 3.3.5.21. Health care providers

There is a rural health center that starts operating 08:00 AM in the morning till 02:00 PM in the afternoon. The long queues are usually found in front of the outpatient department(s). The medical officer examines the patient one by one. Each case pass through paramedic as well (paramedic is often found counseling, answering questions and also distributing the medicine). Medical officers are in most cases locals (from a nearby area). Same as the case with the paramedics and lady health program workers.

There are two *hakeems*<sup>122</sup> in the village (also called as *khandaani hakeem* by the male key informant). The *hakeems* learned knowledge from their respective fathers and grandparents as per a few male respondents. Most of the chronic diseases are usually discussed with the *hakeems* as compared to the emergencies. Hakeem is considered to be the man of wisdom that may even find a cure to the most complex or complicated chronic disease as mentioned by a respondent:

Statement:

*Saday hakeem sahib baray siyanay nay. Asi inhan nu daday par daday tu janday aan.*

Translation:

The Hakeem is a man of wisdom. We (the villagers) know him from his parents and grandparents as well.

The Imam<sup>123</sup> of the mosque is also well famed for his dam (on sugar) to cure diabetes, also on salt and water (for other diseases). The Imam of the mosque is also consulted to wash away the impact (if any) evil eye and black magic. The villagers were found to visit

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122 Hakeem: a physician using traditional remedies in India and Muslim countries. Hakeem is literally from Hikmat which means wisdom.

123 Imam: prayer leader, Mosque leader, Spiritual leader

him for the purpose of getting spiritually healed (not only in case of any illness) as explained by a respondent:

Statement:

*Allah nay Imam sahib nu bara ilm dita aiy. Waday tu wada jado tona lath janda aiy*

Translation:

God has blessed the Imam with knowledge. He can cast away the black magic and other related evil spells.

There are also three pharmacies in the village and are popular in the lowed middle class for medical assistance. A private practitioner also does private clinic in the evening and offer services (both emergency and chronic). The evening timing(s) of the private clinic also help attracting a reasonable number of people. The private practitioner was observed to treat symptomatically (different diseases) and may also refer in case of special reasons/investigations required to the tehsil or district level health facility.

### **3.3.5.22. Marriages and engagements**

The process of betrothal and marriages are done under the supervision of elders of the respective families and also within the community. Most of the girls are still married within the same caste (mostly from the same family) due to several reasons including family honor, social protection, strengthening family bonds. The boys in case there is unavailability of suitable match among cousins may marry outside the family but the caste remain an important decisive factor.

The concept of one's *biradri* (brotherhood) is strongly practiced and it also help developing nexus and web of bonds (mostly done through marriages). The concept of in-laws is very strong for girls and also for the families (with daughters and sisters). The *paika* (girl's parents' house) is often inculcated as a temporary house to the unmarried

girls and *saura* (house of the in-laws) is considered as a permanent settlement. An elderly female respondent shared that:

Statement:

*Mein apnay saas sauray di khidmat keeti tay ajj meri nu tay mera putar meri izzat  
karday nay*

Translation:

I did serve my in-laws with respect and enjoying the same from my daughter in law and my son

The marriage ceremony is preceded by an engagement (*mangni*<sup>124</sup>) in most of the cases. It is a promise between two families of marrying a particular boy with a particular girl. It is a common practice that the *mangni* is at times done in the childhood. Both children are then groomed with the same set of mind (in their respective homes and settings) to marry that particular person. The *mangni* is often solemnized with exchange of gifts (and on regular basis).

The *Nikkah*<sup>125</sup> ceremony is the central activity among all the marriage ceremonies. The Imam of the grand mosque (*Chak 104 NB*) is usually invited who recites the Holy verses

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124 Mangni: Engagement

125 Nikah: a formal, Islamic bond between a man and a woman, thereby declaring the two husband and wife. The term *al-Nikah* (marriage) comes from the Arabic root “*nakaha, yankihu, nikahan*” which literally means “*al-dham, al-wat’u and al-aqdu.*” For example, when we say “*tanakaha al-ashjar*”, the meaning is that “*idza tamayalat wa dhamma ba’dhun ila ba’dhin,*” meaning “when the trees lean against each other, they go on to gather.” The Prophet once said, “*Nikah* is my recommendation, and whoever dislikes my recommendation, dislikes me.” (Hasyim, 2006). The actual marriage ceremony, the *nikah*, during which the marriage contract, the *nikah-nama*, is signed, is performed by the imam. The contract gives written details of the terms and conditions of the marriage, which must be respected by the bride and groom. The imam begins by reading the prophetic sermon for marriage, which includes readings from the Quran; he then awaits the proposal for the wedding from the groom’s side and the acceptance by the bride’s side. The wedding then becomes legal (Monger, 2013).

and explains the philosophy of marriage system and make the parties certain vows and contract (*Nikkah Nama*<sup>126</sup>) is signed in the presence of the assembled (*barati*<sup>127</sup>).

### 3.3.5.23. Deaths

The death rituals resides in various socio-cultural and religious oriented practices. Not that mourning continues for over a month, but also gather extended family (of the deceased) and community members (both Muslims and Non-Muslims) to participate in *soyam*<sup>128</sup> (or *qul*/third day), *nauwan*<sup>129</sup> (9<sup>th</sup> day), *chehlum*<sup>130</sup> (40<sup>th</sup> day) and *salana*<sup>131</sup> (or *barsi*/yearly).

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126 Nikah Nama: Marriage contract

127 Baraati: a group of people from the groom's side, including the bridegroom himself, in traditional Pakistani marriages, who process to receive the bride and bring her to the new home after marriage on the second day of the marriage festival, that is the Baraat. The groom comes back again with a procession (*baraat*) and at this time the bride finally departs with him. It is a happy occasion, although parents may feel a sense of loss over their daughter leaving for a new home (Malik, 2006). In Pakistan when the groom's procession (*barat*) arrives at the bride's house for the wedding ceremony, it is greeted by garlands and rose petals. The wedding usually takes place at the bride's family home. They are accompanied by a band playing wedding songs. On their arrival they are greeted by the bride's relatives and friends with garlands and rose petals (Monger, 2013).

128 Soyam: the third immediate day after the death of a person in Islamic tradition. The relatives of the deceased recite the Holy Quran, so that blessings may descend upon the departed soul and their sins cascade down. Up till third day after death no food is cooked in the house of the deceased. On the third day *Ziyarat*, special prayers are offered by the *Maulvi* (prayer leader) for the peace of the departed soul and a special preparation made of clarified butter, rice and wheat flour, and is distributed among the children and attendants (Singh, Lal, Padmanabham, Krishan, & Mohidden, 2003).

129 Nauwan: the ninth immediate day after the death of a person in Islamic tradition. The day themes recitation of the Holy Quran, and other prayers, for the absolution of their sins. The guests (extended family and relatives) from the far flung areas usually leave (to their respective towns) after the Nauwan or immediately next morning.

130 Chehlum: the fortieth immediate day after the death of a person in the Islamic tradition. After death, the dead body is given a bath and wrapped in a *kafan* and buried in accordance with the customs of Islam. On the fortieth day, all the near, dear and community members are feasted, after the prayers are offered by the *Maulvi* for the deceased. On the fortieth day, the *Maulvi* is presented with valuable articles of the deceased along with food and fruits (Singh, Lal, Padmanabham, Krishan, & Mohidden, 2003).

Most of the people visit the graves of their deceased (especially the grave of the parents) on Thursday (evening mostly) and Friday (both early morning and evening). People also visit the graveyard after both *Eid* (*Azha* and *Fitr*) prayers. The graves are painted (mostly by affluent families) and washed (by the general public). People also take along flowers and natural extract of flowers (especially rose extract/*atar e gulab*<sup>132</sup>).

The tomb of Dr. *Chaudhry*<sup>133</sup> *Nasrullah Khan Ghuman* is mostly revered by other community members (of *Chak* 104 *Shumali*) and has a visible presence in the graveyard. The *Katba*<sup>134</sup> also stated the *Kalema* (in green color), name of Dr. *Ghuman* (in red color), date of death (in blue color), the name of his father (in dark green color).

### 3.3.5.24. Political setup

Political structure of village comprises national and provincial level politics as well as the three tiers of local politics and administration. Village is connected through the seat of national assembly NA 67, also with a provincial level seat. During the elections, national and provincial level politics is very active. The power groups of village become very charged during elections (especially the *Ghuman* family). They mobilize the masses not only in village but also in neighboring villages. The heads of power groups act as intermediaries between national and provincial level politicians and the village community. These heads invite contesting candidates in the village for public address and watch the interests of these politicians to make sure that their supported candidate

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131 Salana: or yearly; death anniversary or a year after the death of a person. Every year on the death anniversary, prayers are offered by the *Maulvi* in commemoration of the dead. A few perform *barasee* (death anniversary) within the household by performing fateha (opening surah of Quran) ceremony (Singh, Lal, Padmanabham, Krishan, & Mohidden, 2003).

132 Atar e Gulaab: Rose flower extract, juice/essence of the rose petals

133 Chaudhry: The surname 'Chaudhry' refers to a person with influence and powerful. So an influential person in a village is called as 'Chaudhry'. The basis of being influential is the possession of land, hailing from a martial race of the Punjab. A Chaudhry is supposed to be well versed in politics, running a men's room, and resourceful by being known in police and district administration, among the judiciary and politicians of all levels. It is basically his support structure that makes him influential and in bargaining position.

134 Katba: Epitaph

manages to win from the area. Regarding local level politics, these political groups overtly participate to make sure that their candidates manage to win. As regards, the local level politics, Union Council (UC) of village is operational as well as the village is also represented in the tehsil and district councils. This is so that *Nazim*<sup>135</sup> (chairman, literally means a Director) of UC represents the village in District council and naib *nazim* (vice chairman) of UC represents village in tehsil council.

According to the male key informant, there is a strong inclination of *Ghuman* family towards an emerging political party known as Pakistan *Tehreek e Insaaf* (PTI)<sup>136</sup>. However, Zulfiqar Bhatti<sup>137</sup> is the current member of national assembly from the said constituency and is affiliated with Pakistan Muslim League (N). The member of provincial assembly from the same political setup is Faisal Farooq Cheema<sup>138</sup>, who is also from the same party as above (i.e., Pakistan Muslim League N<sup>139</sup>). The male key informant expressed it as:

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135 Nazim: *Nazim* refers to ‘an organizer’ on the cities and town level of Pakistan. It is an official post for the local or decentralized government. Each level of local government has elected councils, *nazims* (mayors), and *naib* (deputy) *nazims*. A *nazim* and *naib nazim* are directly elected to the union council on a joint ticket (Akramov, Qureshi, Birner, & Khan, 2008).

136 Pakistan Tehreek e Insaaf (PTI): Pakistan Tehreek-e-Insaaf, headed by former Cricketer Imran Khan. The motto of PTI is Justice, Humanity and Self Esteem. In April 1996, Khan founded and became chairman of the political party Pakistan Tehrik-e- Insaaf (Movement for Justice, PTI). The PTI’s motto advocates “a model moderate Islamic Republic, political freedom, economic opportunity, and social justice.” (Nauright & Parrish, 2012).

137 Zulfiqar Ali Bhatti is the member of the National Assembly (MNA) of Pakistan.

138 Faisal Farooq Cheema is the Member Provincial Assembly (MPA)

139 Pakistan Muslim League (N): The PML-N is the largest faction of the Pakistan Muslim League, and is led by Nawaz Sharif, who has re-emerged as a political player in Pakistan in the past few months after returning from Saudi Arabia where he was exiled after being ousted from power in a 1999 coup led by Pervez Musharraf. The centrist conservative party was in power twice in the 90s, with both terms ending amid damaging allegations of corruption, despite campaigning on an anti-graft platform.



*I see a strong hold of PTI and Pakistan Muslim League (Q)<sup>140</sup> in near future as Mr. Anwar Ali Cheema (late) was elected nearly half a dozen time from the same constituency and he was from the PML (Q) political party. There is still a very strong hold of PML (Q) though PTI is also gaining grounds due to the support of the respected Ghuman family in the village 104 NB.*

### 3.3.6. Characteristics of the study population

The characteristics of the study population (registered patients) are tabulated below, and presented in terms of gender segregation, number of adherents and non-adherents (both male and female – as per the intervention protocols), education, age and follow-up visits (as scheduled and reminded by the public health facility).

Table 7 Distribution of gender and adherence of the study population

	Gender				Total	
	Female		Male		N	%
	N	%	N	%		
<b>Adherents</b>	21	52.5	20	64.5	41	57.8
<b>Non adherents</b>	19	47.5	11	35.5	30	42.2
<b>Sub-Total</b>	<b>40</b>	<b>100.0</b>	<b>31</b>	<b>100.0</b>	<b>71</b>	<b>100.0</b>

The table 1 presented above pictures the number of male and female patients registered at the RHC 104 NB. The female registered patients are greater in number as compared to

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140 Pakistan Muslim League (Q): Pakistan Muslim League – Quaid-i-Azam (PML-Q). The founding political party of Pakistan which led the struggle for independence was All India Muslim League established in 1906. After the creation of Pakistan, it was renamed as Pakistan Muslim League (PML). After the early death of the founding founder the ruling Muslim League suffered from internal factionalism which later resulted in the intra-party conflicts leading to its division. The central leadership was also divided into groups and was unable to perform its earlier function of moderating and neutralizing factional splits in the parliament and the provinces. The Pakistan Muslim League (Quaid-i-Azam) as a dissociated faction of PML, consisted of rivals of Nawaz within PML (N) and those who were scared of persecution by military government parted their ways from the PML (N) (Mahmood, 2015).

the male patients mostly due to the sedentary lifestyle, limited social circle, domestic responsibilities (mostly inbound), patriarchy and stress. The male patients were found to be active in/with wider social circle, ability to decide for health due to financial liberty, enjoys more power in the domestic hierarchy, mobility and activity.

The table also reflects the number of adherent and non-adherent patients as segregated in terms of gender. It is found that the male patients were more adherent (proposed number of visits as operationalized in the introduction chapter) as compared to the female patients. The ability (of male patients) to remain adherent were found to be a socio-cultural construct including the support from the patriarchal structure, finances required for the said decision making, position/status in the family, access to transport and wider social circle. The female patients were found to be generally low towards adherence due to certain dependencies and barriers including need an escort (mostly a male family member) to visit the public health facility, house chores, finances to commute and domestic hierarchy.

The adherence to medication and required lifestyle change is discussed in detail in the same chapter. The above mentioned adherence (required number of visits) were originally taken from the intervention protocol. The methodological segregation of patients in terms of gender and adherence provided initial cleaning of data to be selected purposively for the in-depth study. Both adherent and non-adherent patients were affected by certain socio-cultural factors (as discussed in detail in the same chapter). The explored factors (both direct and in-direct) are further discussed in the discussion chapter along with flow charts (depicting the overall socio-cultural influence on the adherence towards the proposed treatment).

Table 8 Distribution of education status of the study population

	Gender				Total	
	Female		Male		N	%
	N	%	N	%		
<b>Not educated</b>	31	77.5	6	19.4	37	52.1
<b>Primary (1-5 grades)</b>	3	7.5	9	29.0	12	16.9
<b>Secondary (6 -10 grades)</b>	2	5.0	7	22.6	9	12.7
<b>Higher Secondary (intermediate)</b>	2	5.0	1	3.2	3	4.2
<b>Bachelors</b>	0	0.0	4	12.9	4	5.6
<b>Masters</b>	0	0.0	3	9.7	3	4.2
<b>Missing value</b>	2	5.0	1	3.2	3	4.2
<b>Total</b>	<b>40</b>	<b>100.0</b>	<b>31</b>	<b>100.0</b>	<b>71</b>	<b>100.0</b>

The table 2 depicts the situation of education along the gender segregation (of registered patients). It was found that half of the registered patients were not educated at all. Within this category, the female patients outnumbered the male patients. Most of the female patients were found to be not or less educated (as presented above) due to the cultural understanding of becoming a better housewife that may produce and rear the children and household at large. Though, the public and also private schools are available in the locale (but the awareness towards female education is a recent shift). The male patients were comparatively more educated particularly to seek better work/job opportunities plus the culture gave more access and facility to the male community members towards schooling and education in general.

The education factor is discussed in detail in the same chapter as a general factor that may in-directly affect the overall adherence to the treatment (it is somehow insignificant towards adherence as discussed further in the discussion chapter). The formal education does help a patient but not overwhelmingly that it may change the existing lifestyle and perception towards the diabetes care.

Table 9 Distribution of follow-up visits of the study population

	Gender				Total	
	Female		Male		N	%
	N	%	N	%		
1 follow up visit	1	2.5	0	0.0	1	1.4
2 follow-up visits	1	2.5	2	6.5	3	4.2
3 follow-up visits	4	10.0	2	6.5	6	8.5
4 follow-up visits	13	32.5	7	22.6	20	28.2
5 follow-up visits	11	27.5	5	16.1	16	22.5
6 follow-up visits	5	12.5	5	16.1	10	14.1
7 follow-up visits	5	12.5	6	19.4	11	15.5
8 follow-up visits	0	0.0	4	12.9	4	5.6
<b>Total</b>	<b>40</b>	<b>100.0</b>	<b>31</b>	<b>100.0</b>	<b>71</b>	<b>100.0</b>

The proposed follow-up visits (four out of eight visits other than the visit on which the patient got registered) were considered as adherent to the treatment (table 3 shows the follow up visits). It was found that recently diagnosed patients did not attend the initial follow-up visit(s) for certain reasons (regardless of gender) including cross verifying the label and diagnosis from other allopathic sources (especially by physicians who practices at the district level), consulting previously diagnosed patients from the same community, seeking alternate treatment, desire for cure and maximum benefits instead of lifelong management, less trust on the quality and services offered by the public health facility, relying heavily on home based remedies and support treatment (*Chak Mangla* water) instead of modifying the lifestyle (diet, exercise and smoking). However, the later scheduled visits were started getting visited both by male and female patients (through constant reminders by the paramedic) especially after exhausting a number of avenues as stated above.

The follow up visits were scheduled (keeping in view the date of registration) respectively for each patient. Only four (male patients) completed their respective eight

follow-up visits. Most of the patients were able to complete maximum four to five follow up visits (20 and 16 patients respectively). The follow-up visits (though did offer free drugs and lifestyle counseling) remained dependent on the active involvement of the paramedic (by making reminder calls and troubleshooting while delivering the counseling session). The visits were also found to be a socio-cultural construct as most of the female patients required an escort (usually a male family member), taking a day off from work (in case of male patients) as the timings of the RHC was strictly morning, and opportunity cost (as discussed in detail in the same chapter).

Table 10 Distribution of the age of the study population

	Age groups of patients						Total	
	Age= <45		Age= 45-60		Age= >60		N	%
	N	%	N	%	N	%		
<b>Female</b>	19	47.5	19	47.5	2	5.0	40	100.0
<b>Male</b>	14	45.2	16	51.6	1	3.2	31	100.0
<b>Total</b>	33	46.5	35	49.3	3	4.2	71	100.0

The table 4 illustrates the age of the registered patients (segregated with gender). The age of the registered patients has been distributed in three major age groups. It is important to mention that the patients registered are newly diagnosed and most of them fall in the first two groups. Only two females and a male patient is above the age category of 60 years. The age is an important dimension as it affects the overall agility towards roles and responsibilities (both at domestic and community levels). The age was also found to be a general factor that affect the adherence towards proposed treatment due to certain reasons including memorizing the prescribed drugs (number and frequency) as most of the patients are not or less educated (most of the medicine leafs and packs are printed in English), different perceptions about exercise, hard to leave the habit of taste based diet and strong conceptualization towards home based remedies, support and alternate

treatment (as they are easy to comprehend as it is learned, practiced and endorsed with age).

The age brings an extra dimension of home based nursing (especially in case of diabetes). Most of the patients were having a family member (as a treatment supporter) to make him/her understand regarding the required lifestyle change, memorize and (even nurse) the prescribed drugs and escort in case of follow-up visits.

The characteristics of the population as distributed above in different tables are closely related with the overall scope of the current study. The characteristics of the population also helped developing a general picture of the situation (further helped in tracing the registered patients) to understand the episode and journey of/with diabetes. As presented above, there were total 71 patients registered at the rural health center 104 north bound (without any outreach activity). The patients got diagnosed on routine/normal. The study did use the registration data as a basic entry point in tracing the patients in the catchment village (i.e., *Chak 104 Shumali*). The age of the patients made it easier for the researcher to interact (even with the female patients), and the patients had less traditional and cultural pressures (in talking/discussing the issues with the researcher). The aging was found to be respected by all segments of the society as the growing age (of a community member) also promotes (his/her) status/position both in domestic life and social circles. The age of the patient was found to be translated in the local language such as calling *Baji*<sup>141</sup> gee (female in 40s) and *Maan*<sup>142</sup> gee (female 50 years and above). *Baji* is a common term for elder sister and *Maan* for mother, it is also true for male community members such as calling *chacha*<sup>143</sup> gee (male in 40s) and *Buzurgo*<sup>144</sup> (male 50 years and above). The term *chacha gee* (Father's brother) is also interchangeable with *Buzurgo* (respected elder).

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141 Baji: Sister, mostly an elder sister

142 Maan: Mother, Motherly

143 Chacha: Father's brother, here it means fatherly, elderly, respected

144 Buzurgo: literally means elderly, fatherly, respected

The table 3 may be considered as an important set of information that helped researcher to understand the trend of follow-up visits (from initial till last scheduled visits). There were only a few patients who did complete all the scheduled follow-up visits. The adherence to the follow-up visits was compromised for various socio-cultural factors and reasons especially desire for cure and maximum benefits. The adherence to the lifestyle change was also found to be affected and influenced due to certain socio-cultural factors including domestic hierarchy, gender hierarchy, taste preference, space and time for exercise and perceived seriousness of diabetes.

The tables above provided an initial profiling of the situation (it also helped to develop themes for in-depth understanding of the social and cultural factors). The characteristics tabulated above portrayed the basic data relevant to both clinical and anthropological investigations including the adherence and follow-up visits. Apart from the intervention protocols (regarding adherence), the current study also explored the factors that may affect and influence adherence to the proposed clinical treatment and required lifestyle modification.

#### 4. EXPERIENCE AND PERCEPTIONS TILL DIAGNOSIS

The respondents did share their respective perceptions towards etiology (cause of the illness) especially by recalling when they did not know the label of diabetes. They shared their experiences by relating it with certain incidents, traumatic and tragic episodes. The perceptions towards the illness was found to be greatly influenced by the local wisdom regarding tiredness, loss of stamina, frequent urination, obesity and body aches.

Most of the respondents were unsure about the specific etiology of their diabetes condition(s), but did relate it with an episode of stress and trauma. Most of the respondents did relate the cause of their illness with the death of a family member. A few of the male respondents also related it with stress regarding the downfall of business and also the issues of inheritance of property (especially cultivable land) that emerged (as a critical issue) after the death of the father/head of the house.

A few of the female respondents linked the cause of their illness with the concept of *nazar lagna*<sup>145</sup> and *kala jadoo*<sup>146</sup> (mostly claimed as done/spelled by another female family member). The female respondents also generally related their illness with the death of a family member.

It was also found that most of the female respondents did relate their illness with the death of her family members (mostly her blood relations). On the other hand, the male respondents were found to relate it with the stress and trauma caused by the death of family members (both closed and extended family members). A few of the male respondents also linked the cause of the illness with their respective position of becoming the *wada*<sup>147</sup> that is the head of the house (and taking care of the finances, budgets and distribution of property after the death of the father) and also due to the complications

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145 Nazar lagna: Evil eye

146 Kala jadoo: Black Magic

147 Wada: Head of the house; used in a specific context when one takes position/status in the family after the death of a father (previously head of the house).



arising out of the distribution of the property (in case the if he was not senior among siblings).

A male respondent shared that he used to work for naval force and was deputed near the coastal areas. He believed that it happened to him due to the damp environment where he lived in for many years. He further expressed that he also used to be *kalla*<sup>148</sup> and detached from his family back in the village. He expressed it as:

*Meri jithay posting si oo than bari nami wali si tay menoo lagda aiy kay shayd sugar taan kar kay hoi aiy. Kam kaaj bota okha nhi si par ghar di tay bachyan di bari yaad aandi si khaas toor tay duty karan tu baad.*

Translation:

I think that it was the damp environment where I was deputed for years that has caused me diabetes. The work load was not very tiring but I felt very emotional and missed my family after the duty hours (adherent male).

An elderly female respondent shared that she is in trauma since she has lost her elder sister. She emotionally expressed her situation as:

*Lagda aiy kay mera poora jisam odhi yaad vich gal he gya aiy kyun kay oo meri saheli vi si. Umar vich meray toun ziada wadi nhi sit ay meno har velay yaad aandi aiy. Odhi dhian tay ik putar di bari pareshani aiy.*

Translation:

I feel that as if my entire body is melting in her longing as she was my best friend. She was not very old, only two years older than me and I miss her every day. I am really worried about her daughters and a son. (Non-adherent female)

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148 Kalla: alone, to feel all alone

A male respondent shared that her daughter was diagnosed with thalassemia and he used to donate his blood to her as part of the treatment, but she could not survive longer and passed away in a span of two years. He further shared that his entire life revolved around the disease of his daughter. He stated that he did use every available treatment and therapies in his range but she died. He believed that it is the death of her beloved daughter that made him ill (as expressed by him he received the illness).

It was also found that almost none of the respondents related the cause of their illness with being overweight, poor diet habits or lack of physical activity. Only couple of respondents shared that one of their parents had diabetes and it was hereditary in their opinion (as a cause for their illness). None of the respondents related the illness with episode of any other sickness as a cause of diabetes.

A few of the female respondents did share the cause of their illness as a by-product of man-made etiology i.e., caused harm through black magic and evil eye. The complaint of black magic was found mostly in case of female respondents having an active presence of mother in law and sister in law (even if she is married in another village or in the same village) as expressed by a female respondent:

*Viyah day foran baad toun meray tay dabaoo aiy tay naal menoo kamzoori rehndi aiy tay thakawat vi hondi aiy. Meri saas tay nand meray naal nafrat kardian nay. Menoo shak penda si kay meray saurian vichon kisi nay amal tay kala jadoo karaya aiy.*

Translation:

I am under a lot of pressure since my marriage, I am becoming physically weak and tired with time. It is due to the hatred for by my in-laws (mother in law and sister in law). I also think that some of the extended (in-laws) family members were also involved in designing and casting of black magic. (Non-adherent female)

The initial perceptions were mostly related with a tragic episode both in terms of losing a family member and going through stress due to inheritance or business related issues. The initial experience was found to be closely associated with heart sinking, going to bed early, having lethargic attitude and focus less behavior. The female respondents in particular also added the phenomenon of being in the impact and influence of black magic or evil eye.

A few of the male respondents shared regarding the wave of depression and loneliness felt during the early days of the illness. Also couple of elderly female respondents related it with age and associated it with general weakness that emerges with growing old. Most of the female respondents also reported of loss of temper during early days of illness. A female respondents shared:

*Mein kisi tay ghusa nhi kardi, par ajeeb thakavat si jidi wajah toun meri monh mari meri saas day naal, banday day naal tay bachyan day naal vi hui.*

Translation:

I was never angry at people around me and was a calm personality, but due to fatigue I remember of having quarrels with my mother in law, husband and even children.

Most of the respondents shared that they did not share the issues of fatigue, weakness, and frequent urination etc. with anybody and did personal/individual efforts to overcome it. A female respondent shared that she started having hot milk before going to sleep. On the other hand a few of the male respondents shared that they increased the sugar intake to overcome the heart sinking and weakness.

The time and mode of onset was answered specifically in terms of (what year or how many months ago did it happen). Most of the respondents shared different circumstances and year of onset as expressed by a male respondent:

*Meray walid sahib pichlay saal janvary vich foot hoaiy nay. Ami gee walid sahib toun teen saal pehlan foot ho gaiy san. Ami gee toun baad walid sahib di wafat nay achanak dhachka dita. Menoo raat nu baar baar peshab aanda si, pehlay tay mein sochya kay shayd mein raati pani bota peen lag gyan. Baar baar hajat di waja naal wazu nhi rehnda sit ay takleef hondi si kaas kar namaz wastay.*

Translation:

My father passed away in January last year. My mother died before my father around three years back. I was already in a big loss due to the death of my mother few years back and then this death happened. I started having frequent urination after the death of my father last year. I thought as if I am drinking a lot of water with my night meal or before going to sleep. The urination problem also compromised my religious life especially in terms of ablution (for daily prayers). (Adherent male)

A few of the respondents also recalled the occurrence of disease attached with some unusual routine, that was attributed with the possible cause of illness. A male respondent recalled how the holy month of Ramadan (last year) was hard for him in terms of fasting. He shared that most probably due to the *habas*<sup>149</sup>, and long fasting hours (due to summer cycle). He also expressed that he started feeling weak and having body aches. He further stated that:

*Mein apnay ghar di chath tay soota si namaz toun farigh ho kay tay achanak tabiat bari kalli pai (kamzoori mehsoos hoi). Pehlay tay menoo lagya kay rozay namaz di waja toun tabiat kharab hoi aiy par agli raat fair tabiat kali pai. Taay naal saray jisam vich vi dard honda si khaas kar sweray tay raat noo soun toun pehlan.*

Translation:

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149 Habas: Humidity

I was sleeping on the rooftop after the night prayers and felt really bad (weakening in the body). I initially linked it with the tight routine of fasting and prayers but I did feel the same the next night also and I started having body aches especially in the mornings and before going to sleep. (Adherent male)

A few of the elderly female respondents shared that the death of their family members (mostly in recent two years) have actually made them old (old as left alone). The respondents also shared that they started feeling something different (mostly empty inside the body) right after the funeral of their loved ones. An elderly female respondent expressed it as:

*Mera ik he wada pai si tay abu gee toun baad oo he wada si (onhan di wafat toun baad), fotgi toun baad janazay toun baad mera khana peena bilkul ghat gya si. Saray jisam vich khali khali jea mehsoos honda si. Meri lataan vich jaan ve muk gai si kyun kay mera pai meri taqat vi si tay meray yaar vi.*

Translation:

I only had one brother and since he was older than me and was like father to me (after the death of their father), I felt really poor right after his funeral and my diet went meager for weeks as well. The emptiness was all over my body. I was feeling shallow mostly in my legs because I believe that my elder brother was a strength to me and most above of all an emotional support. (Non-adherent female)

A few of the female respondents shared that they started gaining weight (after an episode of stress or trauma). The respondents shared that they initially thought of cutting down the food portions but it did not help. A female respondent explicitly shared that:

*Jeri jooti menoo saal pehlan poori andi si oo katan lag gai. Menoo lagda si kay shayd mein kisi hoor di (wadi beti di) jooti paa lai aiy (wesay meri dheer vi meray jinni aiy).*

Translation:

The same footwear I have been using since a year was biting my feet. I still remember those nights when I thought that I have mistakenly wore/used the footwear of my eldest daughter (though she is of my size). (Adherent female)

Most of the respondents did share the unusual occurrences that was further attributed as the cause for their illness. The respondents generally shared the incidences with the year (also in what season and month), part of the day (as in mid-day or night or middle of night), event (as in funeral, traumatic episode). Some of the respondents also even shared the month (Ramadan) as onset.

Most of the respondents also attributed their onset of illness with symptoms related to the above mentioned occurrences and time. It was generally found that the respondents experienced symptoms such as *khali*<sup>150</sup>, *kamzoor*<sup>151</sup>, overweight, head spinning, blurry vision, frequent urination and body aches.

#### **4.1. Experience and perceptions of physical illness**

The respondents were found sharing different perceptions about complications of illness while answering the current theme. The most common answers were weakness, fatigue, and exhaustion of stamina.

A few of the male respondents also used indigenous terms to express their respective perceptions of illness. A male (adherent) respondent expressed it as:

*Mera tay dil kaala penda si dobda si, tay naal kamzoori wi si*

Translation:

My heart used to sink and remain anxious and I felt weak

Another male (non-adherent) respondent shared his perception as:

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150 Khali: Empty, feeling empty

151 Kamzoor: Weak, weakness

*Maan gee di wafat toun baad na sirf dukh tay dard si balkay meray saray jisam vichon taqat vi khatam ho gai si.*

Translation:

Since the death of my mother, not that I feel low and down but there is this loss of energy in every inch of my body

A few of the female respondents also stated similar perceptions, as expressed by an elderly female (non-adherent) respondent (while touching her both calves and legs):

*Menoo aithay khali khali mehsoos honda si*

Translation:

I used to feel so empty here

Another female (adherent) respondent expressed her perception as:

*Mein Chaudhry sahib di haveli vich kam karni aan. Menoo lagda si kay meri roz kam karan di taqat ghatdi ja rahi aiy. Pehlan mein sara kam dopeher tak muka leni saan par hun sham pay jandi aiy. Hun kam day doraan saanh vi lena penda aiy tay raat tak bari thakawat hindi aiy*

Translation:

I work for *Chaudhry sahib* (at his *haveli*). I started feeling as if I am losing my stamina every day. I used to complete most of my responsibilities by early afternoon but now the work goes beyond late afternoon. I take more breaks while completing the chores and also feel tired at the end of the day.

A male (adherent) respondent also shared his experience of losing the stamina and feeling tired as mentioned below:

*Pehlan mein baray kam naal naal kar lenda si tay chalan phiran tay khatoon vich vi koi lachari nhi si. Hun menoo kam kaaj wastay motorcycle lena peya aiy. Hun tay ik ghanta vi khloo nhi honda tay agay mein sara sara din faslan da raakha kar lenda si.*

Translation:

I used to do multiple tasking and was never tired of standing and walking for hours. I have recently bought a motorcycle for the purpose of my daily commute. I cannot stand for even an hour now, earlier I used to stand for hours to monitor my fields.

## **4.2. Reaching health facility**

It was found that almost all of the registered patient (at the said health facility) did not directly reach or consult the health facility as their first option. Most of the respondents were found to discuss the emerging symptoms initially with the family and nearby family friends leading it to see the local herbalist and holy man. It was also found that most of the respondents (both male and female) did visit at least once the above mentioned options. A few of the registered patients also visited the shrine located near the village for the purpose of spiritual healing.

All of the male respondents did visit the paramedic (informally) before consultation and diagnosis. It was found that the male respondents generally discussed the situation with the paramedic in the evenings, since evenings are comparatively freer and offer more space for social gatherings and meetings. The female respondents, however discussed the issues mostly with their peer group in the mornings and mid days, since for them it was easy to find time during and after house chores.

It was also shared by the respondents (both male and female) that they did consult the already diagnosed patients in the vicinity who had similar symptoms. The role of paramedic was found of extreme importance as most of the respondents did discuss and



rely on his opinion especially regarding visiting the rural health center as mentioned by an elderly woman who was also handicapped:

*Meri rakh chak mera putar tay meri noo karday nay. Mein apni noo day naal ik waderi nu wekhan gaiy si jeri kool ai rehndi aiy tay sugar di mareeza aiy. Oos day akhian asi doctor sahib (paramedic) nu milan wastay gaiy warna asi dispenser sahib kool jana si. Doctor sahib (paramedic) nay meray putar nu mat dassi kay jald tu jald hospital chakar laa loo ta 'kay ilaaj hovay.*

Translation:

I rely on my son to transport me. I am also dependent on my daughter in law. With the help of my daughter in law we went to see another elderly woman who lives in our neighborhood and is also a patient of diabetes. She forced us to meet the paramedic and not to consult the dispenser who sits at a local dispensary. Paramedic not only convinced me but also my son to take me to the rural health center as soon as possible for initial examination and tests. (Adherent female)

It was also found that none of the respondents got diagnosed on their first visit to the health facility. Most of the respondents had to come again and even for the third time especially regarding the test of fasting blood glucose. Most of the respondents confused the instruction(s) regarding the fasting blood glucose. Most of them considered a cup of tea or a fruit as fasting as expressed by a female respondent:

*Meri sugar teesray chakar tay check hoi si kyun kay menoo pata nhi si kay khali paat da asal ki matlab aiy. Dosray chakar tay mein sweray tarkay chaa pee lai si tay doctoran nay wapis ghal dita. Teesray chakar tay fair akheer meri sugar check hoi.*

Translation:

I got my fasting blood glucose done on the third visit as I was not even aware of the right meaning of fasting. On my second visit, I had a cup of tea early morning

and was sent back. Finally, on my third visit I managed to remain fasting for the test. (Non-adherent female)

It was found that most of the respondents did not accept the labeling of being a diabetic. Nearly all of the respondents went for second opinion. It was shared by most of the respondents that the doctor who does clinic in the city or sits in the district head quarter hospital has a better understanding and his expert opinion is more reliable and authentic. To confirm the diagnosis most of the respondents also discussed their individual cases with the peer group and family members for opinion as shared by a male respondent:

*Mein kam toun do din di chuthi lai tay waday hospital (district head quarter) chakar laya tay unhaan nay vi dasya kay menoo sugar aiy. Doctor sahib nay vi menoo sugar check karan da pora nizaam samjhaya. Hun mein apnay RHC toun he check up karwana.*

Translation:

I took two days off from my work and went to the district head quarter and it got confirmed that I am a diabetic. The doctor at the DHQ also briefed me regarding the standard procedure of diagnosis. That greatly helped me to rely on my rural health center for follow up checkups. (Adherent male)

A few of the respondents also visited the already diagnosed diabetics from the same community to discuss their experience of disease. The respondents took their respective opinions as a road map to cross validate their own. Based on the discussion, the respondents started devising a strategy to cope and manage with the label of diabetes.

#### **4.2.1. Prescription and drug intake**

It was found that there are three major steps of prescribing the treatment starting from the lifestyle modification and adding a (drug) with it. The step two adds insulin therapy to oral drugs (especially in case of severe associated conditions). The third step is to label as non-responding diabetes and may be further referred to tertiary care.

No respondent was found to be insulin dependent as nearly all of them were recently diagnosed and were prescribed for the first step as mentioned above. The respondents did not find the drug intake as complicated as it was in the case of understanding the process of fasting blood glucose. However, most of the respondents did not find one *goli*<sup>152</sup> as an effective medication to treat their diabetes as mentioned below:

*Aiy ik goli nay ki karna aiy? Ik goli day naal saari sugar da ilaaj kis tarah ho sakda aiy. Menoo tu taap tay sar dard vich do golian naal araam andaa aiy. Menoo nhi lagda kay is naal sugar theek hovay gi. Mein dispenser noo vi wakhaya aiy tay Sargodhay shehar vi chakar laya aiy.*

Translation:

What can this one pill do? It is just one medicine for my entire diabetes. I used to take at least two pills in case of fever and headache. I don't really think that it is effective. I have consulted the dispenser and also went to see the doctor in the Sargodha city for the same purpose. (Non-adherent female)

A few of the respondents (both male and female) shared that they doubt the quality of the drug prescribed and given by the rural health center. It was also shared that because this medicine is provided free of cost, and its quality is doubtful in that case as well. The respondents who could afford went to the private practitioners and also DHQ.

*Pehlan tay ik rupaya lenday san tay hun mufat parchi bandi aiy. Menoo pata aiy kay aithay dawai vi changi nhi honi jevain poray nizaam di halat aiy.*

Translation:

Initially it was one rupee, now it is free of cost to visit the RHC. I am sure that the quality of medicine is low just like the service provision (non-adherent female)

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152 Goli: Tablet, also used for medicine

A female respondent shared that I am not being administered with injection(s) and I have come to know that I need to take these medicine(s) for the rest of my life. She believed that diabetes is a curable disease.

*Aiy dawai tay ilaaj hun zindagi day naal naal he chalna aiy? Menoo tu aam cheezan vi bhul jandian nay kyun kay mein budhi ho gai aan tay naal talaq vi.*

Translation:

How can I afford the medicine for the rest of my life? I forget simple things as I am an old woman and a divorcee. (Non-adherent female)

It was found that a few male respondents made a home based chart to daily check and schedule the medicine. A respondent shared that he has dedicated few pages on his diary that he keeps with himself to manage his farm business. He said that by that way he get reminded of taking medicine(s) on time.

It was found that a few respondents went to see a private practitioner because he prescribed more than one medicine to manage their current situation of diabetes. A female respondent shared that she asked her son to get the drugs from the pharmacies in the Sargodha city as the pharmacies in the cities are of better quality. Another female respondent shared that it is better to buy quality medicine instead of having free of cost low quality medicine from the RHC.

It was found that a few female respondents administered on their own as stated below:

Statement:

*Goli da size sada aiy kay is vich kina asr aiy. Mein tay apnay hisaab kitaab naal he goli dawai khani aan tay naal waqat vi badal lai da aiy.*

Translation:

The size of the pill does define the quantity within. The frequency may be managed keeping in view how I feel at a particular part of the day. I also changed the timing(s) of my medicine (non-adherent female)

Statement:

*Menoo hospital toun ik mahinay tay pandraan dinan di dawai mili sit ay mein bari aqalmandi naal do mahinay istimal kiti aiy tay ik phera vi bach gya tay naal aglay pheray wastay pesay ikhatay kar laiy nay.*

Translation:

The RHC gave me the medicine for one month and fifteen days but I have wisely used it for over two months. By that way I have saved a visit and resources to make another visit to the RHC (non-adherent female)

Some respondents on the other hand shared that there is nothing wrong with the prescription of RHC. They further added that he had cross checked it with what the doctors have suggested and prescribed at DHQ as well. They also mentioned that it is the same drug that is available on different drug stores of Sargodha city, and the medicine given at RHC is of the same quality as available in the city.

#### **4.2.2. Follow-up for clinical treatment**

It was found that most of the respondents were encouraged to make follow up visits to the RHC every month. The follow up visit(s) was considered a major factor of adherence. However, few below mentioned areas were found significantly important towards adherence.

Most of the respondents found private clinics as a more feasible option for a follow up visit/checkup. It was found that the private practitioners run their clinics/hospitals in the evening as compared to the public health facility which is strictly morning (08:00 AM to 02:00 PM). The timing(s) of the private clinics allowed both male and female diabetics to visit in the evening, especially in case of females who remain busy in house chores and

usually visit health facility escorted by a male member or an elderly woman. It was also found feasible for the male patients who could visit the private health facility in the evenings, especially where most of the respondents are either retired from a public job but daily wagers or doing a farm business.

Another important dimension was discovered that is related with the travel and day cost to visit the public health facility as emotionally explained by a female respondent:

*Mein hospital 104 shumali toun koi pandraan kilometer door rehni aan. Tay naal mein mazoor vi aan. Mera hospital baar baar chakar lana sokha nhi, menoo har chakar tay pesay lanay pendaay nay tay naal mazoori wakhri aiy.*

Translation:

I live at least 15 kilometers away from the RHC 104 NB. I am also handicapped and a wheel chair dependent. It is costly for me to travel once a month and also to travel this far with my current situation. (Non-adherent female)

Another female respondent said that she is a divorcee and living with her parents and it is very hard for her to request her parents to afford the monthly travel cost for the follow up visit. Since she does not have any source of income and divorcee is usually considered less in domestic decisions. She further added as:

*Mein apnay maa peo day naal rehni aan tay talaaq toun baad kon kidi gal sunda ya manda aiy. Mein tay ghar vich ik pasay he rehni aan kyun kay hun mein ki keh sakni aan.*

Translation:

I am so dependent on my parents and being a divorcee brings me to a point where I cannot demand or ask for anything extra. I am living in a corner and not allowed to say much due to my current position. (Non-adherent female)

A few of the female respondents shared that it is feasible for them to visit a nearby private health facility and also other options that may include spiritual healer, quacks, dispenser, herbalist and home based remedies. Most of the respondents considered these options economical and may be managed with common local wisdom. However, adherent patients were those who remained in contact with the paramedic that kept convincing the diabetics to stay regular for follow up visit(s). Most of the adherent patients said that the phone call by paramedic for reminder of follow up visit to the RHC was not only helpful in remembering the date of follow up but it also reinforced the importance of the follow up visit for the health of the patient.

An elderly female respondent said that she has seven sons and five daughters and one of her sons used to work abroad and brought her the glucometer and a blood pressure apparatus so that he may get her diabetes and blood pressure checked daily and easily when required. She further added that:

*Allah da bara shukar karni aan kay Allah nay menoo aisa putar dita jera mera khyaal karda aiy. Aiy roz meri sugar check karda aiy tay naal menoo har mahinay hospital vi check up wastay lay kay janda aiy. Meri khatar ik motorcycle vi lai aiy kay koi zarurat pay javay, taan ai taraqi kar rheya aiy.*

Translation:

I am so thankful to the Almighty who has blessed me with such a caring son. He checks my sugar (diabetes) daily and also takes me to the RHC every month. He is so generous and kind, that is exactly why his farm business is flourishing. He has dedicated a motor bike for me and keeps it ready for any emergency or when required. (Adherent female)

A male respondent also added that since he is working nearby the RHC and he is also regularly in contact with the paramedic. Both the proximity and contact with the paramedic helped him to visit the RHC for nearly every required follow up. He also added that:

*Mera daftar RHC day naal he aiy tay naal paramedic day naal salam dua vi aiy, haftay vich ik dil mulaqat ho he jandi aiy. Oo menoo roti tay warzish yaad karwanda rehnda aiy tay naal naal taranda vi aiy.*

Translation:

I work few buildings away from the RHC and now I also know the paramedic and I meet him at least once in a week. He does remind me to modify my lifestyle also help me understand the further complications if I may not manage my diabetes. (Adherent male)

It was found that most of the respondents considered diabetes as a curable disease, especially female respondents perceived it a disease that may be cured by any other available claims and hence considered other options including ways to spiritually heal the illness, manage it with economical home based remedies and seeking any other channel that claimed to cure the diabetes such as the well-known and well-famed water from a nearby place known as *Chak Mangla*.

#### **4.2.3 Sugar is not permanent**

It was found that most of the respondents did not consider sugar (a common term for diabetes) as permanent. It was also found that both male and female respondents claimed that it is a curable disease. Respondents started seeking knowledge regarding certain claims (to cure diabetes) available as supplement/support and alternate treatments (discussed in detail further below). Most interestingly, nearly all of the respondents relied on the allopathic opinion for the diagnosis (after exhausting other local options and opinions) but varied greatly in terms of seeking treatment (to find cure for diabetes in most of the cases). Most of the respondents were eager to find and discuss maximum benefits or cure through other methods and available claims/treatments.

It was found that very few respondents adopted the permanent sick role even after being diagnosed as a patient of diabetes, neither did it cost any major hindrance in the social life especially work life (of male respondents) and domestic responsibilities (in case of



females) as all of the patients were newly diagnosed. Only a few patients were found who took off from their respective jobs to get the checkup done from the rural health center. A female respondent who works at the house of Chaudhry sahib (as a maid) had to take a week off (her husband took the request to the Chaudhry sahib) and was granted to get herself checked. Since her diagnosis and initial medication, she started working on the same old routine.

Most of the male respondents did not consider their diabetes as severe disease, rather a few of the male respondents called it a timely disease and shared that it will get cured with an indigenous along with allopathic treatment(s), as expressed by a male respondent:

*Vekho gee! Jay koi shay ho sakdi aiy (kharab ho sakdi aiy) tay sahee vi ho sakdi aiy. Aiy wadi gal nhi tay naal menoo koi ziada dard vi nhi aiy. Menoo lagada aiy kay aiy thakawat waghaira umar day naal naal aiy. Mein ilaaj labh rheya aan tay theek ho javaan ga.*

Translation:

Look! If something can happen it can also be reversed. It is not a big deal and I don't feel any severe pain in my body. The fatigue is due to my aging, rest I am fine. I am seeking a treatment that will cure it soon. (Non-adherent male)

However both male and female respondents, did share their fear regarding losing a leg in case of emergency. Most of the respondents did relate the losing of leg (through an operation) due to diabetes as a narration of an earlier example from the community. However none of the respondents shared the fear of losing eyesight or kidney failures due to diabetes.

A female respondent shared that not only she knew the person whose leg was operated due to diabetes but was also aware of the complications that arose in his life due to the mismanagement of it. A few of the female respondents also called diabetes as a lifelong disease in a way as expressed by an elderly female respondent:

*Mein budhy aan tay kamzoor vi, tay menoo lagda aiy kay meri sugar qabar tak meray naal he javay gi. Menoo lagda aiy kay is da ilaaj ho sakda aiy par meri umar di waja naal cheezan okhian nay.*

Translation:

I am old and weak, and I believe that my sugar will get buried with me in my grave. I don't say that it cannot be cured, but my situation is different and my age is an important factor towards my diabetes. (Non-adherent female)

Most of the patients believed that there has not been any (severe) complication in their lives so far due to diabetes, whereas only a few respondents (both male and female) shared that it must be managed and handled clinically (especially allopathically) in order to avoid any complications that could arise due to disturbed glucose levels.

Tabulated summary of the experience and perception till diagnosis

Adherence	Experience and Perception till diagnosis			
	Perceptions towards etiology	Perceptions towards physical illness	Reaching the health facility	Follow-up for clinical treatment
<b>Male</b>	Trauma, Tragedy, Staying away from home	Loss of stamina, Anxiety	Influenced by consulting the Paramedic in the evening (after office hours) and peer group	Afford to pay the opportunity cost by visiting on the scheduled follow-up visit(s)  Role of paramedic
<b>Female</b>	Black magic, Evil eye, Death of a blood relative(s)	Emptiness, Weakness	Influenced mostly the peer group especially meeting in the morning and mid-days after completing the house chores	Dedication and financial situation of the treatment  Role of paramedic in convincing and motivating the treatment supporter
<b>Common Factors</b>	Feeling of loss i.e., physical, financial	Shallow and hollow feeling especially in the	Consulted the already diagnosed	Financial affordability

	psychological	legs	elderly patients in the vicinity and community	Education and exposure of the patient or treatment supporter (especially in the case of females)
<b>Non-adherence</b>	<b>Experience and Perception till diagnosis</b>			
	<b>Perceptions towards etiology</b>	<b>Perceptions towards physical illness</b>	<b>Reaching the health facility</b>	<b>Follow-up for clinical treatment</b>
<b>Male</b>	Trauma, Tragedy, Staying away from home	Loss of stamina, Anxiety	Influenced by consulting the Paramedic in the evening (after office hours) and peer group	Opportunity cost  Perceptions towards curability of diabetes
<b>Female</b>	Black magic, Evil eye, Death of a blood relative(s)	Emptiness, Weakness	Influenced mostly the peer group especially meeting in the morning and mid-days after completing the house chores	Lack of family support  Perceptions towards curability of diabetes
<b>Common Factors</b>	Feeling of loss i.e., physical,	Shallow and hollow feeling	Consulted the already	Diabetes is not a permanent

	financial psychological	especially in the legs	diagnosed elderly patients in the vicinity and community	disease, and may be permanently cured by other methods
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The table above was designed to summarize the experience and perception of already mentioned categories of registered patients till diagnosis or more clinically how they have reached the health facility. The experience and perception till diagnosis is divided into four sub-categories including perceptions towards etiology, perceptions towards physical illness, reaching the health facility and follow-up for/of clinical treatment. The experience and perception is tabulated basically in two broad dimensions including adherence and non-adherence. The adherence and non-adherence is further divided as experience and perception shared by male and female plus if there are any common factors between the genders.

The perception towards the etiology played an important role in sharing, discussing and deciding regarding seeking the appropriate treatment. The perception towards physical illness was though found mostly similar across the table both in male and female as compared to the perception towards etiology where female had strong perception towards metaphysical or supernatural forces or death of a blood relative.

It was commonly found in most of the patients that they consulted regarding their physical conditions before reaching the health facility. It was also found that all of the registered patients used the allopathic label to further discuss their post diagnosis verification and further management of their diabetes.

It was also found that the role of paramedic played a crucial role towards reaching the health facility especially in case of adherent male patients. The paramedic also influenced the decision making towards the above mentioned category of the patient.

The non adherent patients were found to be influenced by local perception of curability of the disease, finances, lack of family support and trust in the services of the public health facility.

## **5. EXPERIENCE OF ADHERENCE TO CLINICAL TREATMENT AND FOLLOW UP**

Adherence to the follow up visit(s) was generally found hard for the respondents. It was though found that nearly half of the registered patients (also my respondents) remained regular in visiting the health facility (however, the follow-ups were done in different or random months but not consecutive). The adherence to the follow up were generally found in the male patients with an exposed background especially those who have been working in the cities generally with public institutes. The background is similar even in case of adherent females where the treatment supporter (usually a male family member) had exposure and usually escorted in the scheduled follow up visits.

As mentioned above, most of the respondents did try other available options that may be categorized as support/supplement treatment that included water from *Chak Mangla* and home based remedies (used and tried by all of the respondents both adherents and non-adherents). The alternate and supplementary treatments were also found to be a reason behind compromised adherence among few respondents including mostly herbal treatment and spiritual healing. It was also found that a reasonable number of respondents consulted private practitioners and mostly a quack or a dispenser instead of making regular follow up visits to the RHC. The above mentioned categories were exhausted by the respondents and it compromised and delayed adherence to the important treatment component (i.e., follow up visits).

The common features of the above mentioned categories included claim that it may cure the disease once and for all; economical; locally endorsed; easy to manage; simple to comprehend; consensus of the family members and experienced by the former diabetics. Most of the respondents therefore preferred and were found to seek cure and maximum benefits instead of routinizing the follow up visits. The idea of getting cured was found throughout underlying the cure seeking behavior.

### 5.1. Case study of *Chak Mangla* water

The support/supplement treatment was found to be the most common activity/hindrance that compromised adherence to the follow up visit and clinical treatment in general (in terms of delayed visits). However, the supplement treatment never claimed or forced its consumers to stop the allopathic medicine or treatment at large especially in the case of water consumption (for 40 days at least) from *Chak Mangla*. It was found that all of the respondents tried and used the *Chak Mangla* water at least once after being diagnosed.

The water tap which is famously known to cure diabetic illness is located in *Chak Mangla*, a little off *Jhang*<sup>153</sup> road in Sargodha, and is reportedly visited by a large number of people from around Pakistan. The *dera* upon which the tap is situated belongs to a village local who manages all the duties and affairs associated with distribution of water. It was found that various myths and beliefs existed in and around Sargodha about the healing powers of the water from this tap. The respondents also confirmed their belief in the efficacy of the water in healing their illness permanently. Respondents informed that consuming this water regularly for at least two weeks can keep the sugar (diabetes) under control and eliminates the user's dependency on all other forms of medication (though none stopped taking the drugs).

The *dera* is located amidst fields of cotton and mustard and is reached via a dirt road through the fields. The visitor will encounter, on a typical day, that the path leading to the *dera* has little roadside stalls at regular intervals that are selling large water cans (see Fig 6). The shopkeepers revealed how the water cans are the top most item being sold as the visitors travelling to this place are often purchasing them in large numbers.

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153 Jhang is the capital city of Jhang District, in the province of Punjab, Pakistan. It is situated on the east bank of the Chenab river.



Figure 6. Roadside stall selling water cans on main Sargodha road



The water from this tap has gained a lot of popularity since past 3 years, and the place has been frequently visited by researchers, scientists, doctors, news reporters, religious officials from nearby villages, as well as politicians and other notables. It has also been covered by local and national newspapers, TV channels (as heavily claimed by the owner) and popularized through YouTube as well<sup>154</sup>. The place has been an attraction for people not only suffering from diabetes, but also a range of other diseases. Although the diabetic patients outnumber others in frequency, however the belief about its healing capacity is not just limited to diabetes alone. It was witnessed that there was an increasing number of people who were suffering from arthritis, asthma, childlessness, indigestion, tuberculosis, acidity, jaundice as well as obesity who were visiting this place to seek cure for their diseases.

A visitor respondent had been collecting water from the tap since 2015 for his brother suffering from Diabetes. Every month, he visits the dera to collect 4 gallons of tap water for his brother back in *Chenab Nagar*.

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154Video footage showing tap being swarmed by people collecting water.

<https://www.youtube.com/watch?v=yKNr7sTFTzk>

[https://www.youtube.com/watch?v=bemd0ueB9q0&ebc=ANyPxKrgKp6ihZuOBdr7w6RIMbZLmDOvUXSGNiT9S24rOQ5WZgesKeW644EqBKFXA\\_Yi3qVwAr-7DYPKNBCisBmXrjxK5e35hg](https://www.youtube.com/watch?v=bemd0ueB9q0&ebc=ANyPxKrgKp6ihZuOBdr7w6RIMbZLmDOvUXSGNiT9S24rOQ5WZgesKeW644EqBKFXA_Yi3qVwAr-7DYPKNBCisBmXrjxK5e35hg)

*“My brother has had diabetes for past 6 years, and often times his sugar level would shoot up and we would rush him to the emergency. He had been regular with his medication, diet and walk however it was not proving to be adequate in controlling his sugar (diabetes). We had been hearing about chak mangla from a lot of people, perhaps for almost a year. One of our neighbors had mentioned it to us several times, but none of us took note. One day, around 6 months ago, my mamu (maternal uncle) came to our place in a rush asking for empty cans of water. He explained how he had been using this water for two months and his sugar (diabetes) had been improving, and that he had run out of water and someone was going to chak mangla, so he needed the bottles to stock up for the coming month. It occurred to me then, that there would be no harm in trying and I gave him an extra water can for my brother. My brother staunchly believed in allopathic medications, and he resisted using the water once it had arrived. The water kept lying in our kitchen for the next month, and one day as we were out of drinking water, my brother started to drink from the bottle that had come from chak mangla. It was then that he began to notice improvement in his health, right after a week of use. My brother expressed in the months that followed that he felt overall healthier, less tired and more active and his sugar control had improved tremendously”.*

It was also noticed during visits to *Chenab Nagar* and other nearby areas, a city located around 70 km from *Chak Mangla*, that a large number of rickshaws displayed banners that claimed to be selling ‘water from chak mangla’ (see Fig 7).

Figure 7 Rickshaws at the dera collecting water to sell



A respondent confirmed that these rickshaw drivers regularly travel to chak mangla with as many water gallons as their vehicle can accommodate and return to the city to sell it to their customers. Another respondent shared how some of these rickshaw drivers deceptively sell plain water under the label of '*Chak Mangla*' as it becomes cumbersome for them to travel all the distance to *Chak Mangla* and obtain water since the queue leading up to the tap during summer counts in thousands, as confirmed by three separate respondents. (See Fig 8 and 9)

Figure 8 Long queues of visitors during summer



The manager of the dera narrated how the water tap has existed since somewhat 20 years, however it only received the overwhelming attention recently.

“About 8 years ago, a village local suffering from severe acidity came to visit us. He stayed at the dera for two months and was only drinking water from here. By the end of two months, his acidity had completely vanished and he continued to take water from the same tap afterwards. Likewise, my own father had sugar, and he noticed when he restricted the source of his water intake only to this tap, he did not feel the need to control his sugar (diabetes) through other medication. From there, the word began to spread.

Figure 9 Long queues of visitors



The owner proudly claimed that today, we have visitors from *Kashmir, Afghanistan, Peshawar, Thatta, Thar, Nankana Sahib, Jhang, Lahore, Khariyan*. A visitor also sent bottles to his diabetic relative in Canada, and one to Saudi Arabia. Trucks that move along the GT<sup>155</sup> road traveling to Sindh and Gawadar regularly stop here to fill their water cans and deliver it to people along the way. I don't know how the word has travelled so far and wide, I think it is all because people actually get healed from here. I often get confused and ask people who keep returning, that are you even getting any benefit from here. One visitor replied, ‘brother, I'm 60 years old, I spend PKR<sup>156</sup> 4000 on petrol on every visit and I borrow this money so I can return it in installments later, why else do you think I would be going through all this trouble if it wasn't helping me heal’.

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155 GT road is Grand Trunk Road

156 PKR is Pakistani Rupees

A worker at the site added; “We have, even in this winter, 5-6 rickshaws daily coming from different nearby areas especially Sargodha. The place gets most visits in summers, and on Fridays and Sundays. People start to gather here as early as 5 am, and we come here and attend them right after the morning prayers (Fajar). The DPO (district police officer) chiniot<sup>157</sup> visits almost every alternate Friday and I still get calls from him from time to time. When he came here first, he had to take insulin every day, and after regular use of this water, he doesn’t take any insulin and stays healthy.”

The water tap recently got affixed to an electric motor, and is now operated through a sophisticated apparatus that was gifted to the manager from a regular visitor (see Fig 10). The manager emphasized how the visitor who made the generous contribution was a member of *Tableeghi Jamaat*<sup>158</sup>, a religious zealotry organization which is a strong opponent of the manager’s faith. He joyously explained how this tap brings people from everywhere regardless of religious diversions and enmity. The apparatus, that uses the motor to maintain pressure and flow, runs along at a two meter horizontal length and has several taps of various sizes attached with it to adapt it to various types of storage cans.

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157 Chiniot is a city and the administrative headquarter of Chiniot District in the state of Punjab, Pakistan. On the bank of the river Chenab, it is known for its intricate wooden furniture, architecture, havelis, and mosques.

158 Tablighi Jama’at: a group of people who preach their own set of religious beliefs and principles. The bulk of academics and other observers see Tablighi Jamaat as peaceful, apolitical, and law-abiding: As political scientist Mumtaz Ahmed has written: “In fact the Tablighi Jamaat detests politics, and does not involve itself in any issues of sociopolitical importance.” (Scott, 2007).

Figure 10: The modified tap system



The manager shared how this has helped to ease and fasten the process of water generation to accommodate the increasing number of visitors. He also shared that the water from the tap is free for all, and he doesn't place any charges on the acquisition of water. Instead, he has to hire a few paid workers during the peak of summers when the visitors come in large numbers and things become difficult to manage but he claimed to do it as a form of charity.

A small covered construction at the site was also observed, which the manager of the *dera* informed was a washroom for ladies and gents (See Fig 11). He shared how he had them constructed last year as the visitors coming from far flung places began to grow in number and faced numerous difficulties related to the lavatory situation (especially the diabetics).

Figure 11: Recently constructed washrooms for the visitors



The owner explicitly explained how he took no money from any of his regular visitors despite their insistence.

*“I never demanded anything in return from people, but some affluent visitors always try and respond in cash and kind. Although I never actively advertised about this water, still the word keeps on spreading. This is not a business, people come here and get healed, and I take no money from them. I’m doing it so I get the reward from God, maybe this way I will earn some blessings. One time, a man came from Sialkot and he had no money to buy the plastic can, neither the money to go back. So I offered him to stay, gave him a can and filled it with water and gave him the money for his journey back home”.*

The popularity of the tap hasn’t just resulted in large swaths of people being attracted to the site, but has also yielded a number of undesirable and rather difficult circumstances for the people at the *dera*, ranging from negative propaganda against the owners of the land as well as competitive rivalry and parallel campaigning to cause a dent in the popularity of the tap. The locals at the *dera* reported at having faced with numerous off-putting situations, one of which included religious vilification and rancor against them. “We are *Ahmadi*, and although people from far off places visit and offer great respect despite knowing about our faith, the locals have a real problem. They can’t digest the fact

that the tap water is getting so much popularity. They printed wrong information and profanities about us and used extremely foul language in the local newspaper, trying to discourage people from coming here. They also assert that under the guise of healing, we advertise or preach our religion to others. God knows that we do no such thing here, why would people still come here and have friendly terms with us if we were preaching our religion to them? Like I said, the leader of *tableeghi jamaat* is regular visitor and friend, so you can imagine, religion has nothing to do with it. We are linked to them through humanity.”

The manager also explained and claimed how a local opponent set up a similar water tap nearly three kilo meters from the site in order to disorient the people coming here. “He actively publicized and campaigned for his tap, and had posters printed all over the village. He even ran an advertisement on news channels claiming that water from the tap on his land has healing properties. He even boasted with a long list of diseases claiming that the water heals all of them. And now you can go and see, that tap is seen nowhere, people hardly responded and all his efforts were in vain, whereas we make no effort or campaigning and still people keep coming.

The manager of the *dera* also quoted a few dreams related to the water tap and explained how he believes they have manifested in form of a huge following being witnessed today. “Around 3 years ago, while the knowledge of the tap was still very limited, my *Bhabi*<sup>159</sup> saw a dream that there is a water tap in the fields near the *dera*, and all the world is drinking water from it and the water never finishes. We see how this dream is coming true, it is all God’s doing. Another young man from *Chenab Nagar* came here one day and explained how this place was shown to him in a dream. He had been struggling with diabetes, and one night he was shown the way leading up to the tap and was told that he would be healed from here. The young man swore that he had heard from no one about this water, nor did he ask anyone for directions, and only followed the way as he was shown in the dream”.

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159 Bhabhi: brother’s spouse/wife in traditional language.



One attendant at the dera recalled another incident where a man came with his mother, and he had to lift his mother in his arms to bring her from the rickshaw to the tap. Her knees had severe pain and she could neither walk nor stand. Within a week's time, the woman returned to Faisalabad and walked on foot easily without any help.

It was also noted how the manager at the *dera* kept written records in form of diaries of all the impressions and experiences that the visitors had shared with him. It was a well-furnished record which included the name, phone numbers and other details of the visitors with short summary in the visitors own handwriting of how the water has affected his or her illness. The manager shared those diary entries with the researcher and explained how the beneficiaries recorded in diary can be spoken with for a follow-up research.

The healing that comes from the water has also led to some beliefs and rituals, which the manager referred to as uncalled for and resulting from lack of knowledge of the people. "People distribute *daig*<sup>160</sup> (cooked food), they often times bow down or hug the *peepal*<sup>161</sup> tree, or even kneel down and try to touch my knees while rejoicing their restored health. I do not condone these rituals, in fact I dutifully condemn them, none other than God has the power to heal, and these things lead to rituals and customs which have no place in Islam."

The manager and his staff also shared a few medical reports with the researcher, and explained how they regularly have the water tested for any oddities in its mineral composition. They sent the water for several lab tests, in Lahore as well as Faisalabad. Each time, the lab report not only confirmed that the water was safe for drinking but also that showed the rich mineral components found in the water, reporting higher than usual levels of calcium.

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160 Daig: a big, round pot, made up of steel, used for cooking purposes in Pakistani culture, mostly for larger gatherings or occasions such as marriages, religious processions.

161 *Ficus religiosa* or sacred fig is a species of fig native to the subcontinent and Indochina. It belongs to the Moraceae, the fig or mulberry family. It is also known as the bodhi tree, pippala tree, peepul tree and ashwattha tree.

The rich mineral composition may be a result of two things, according to the manager. One reason could be the old peepal tree that has existed for hundreds of years, and the resultant combination of minerals could be due to its shade or its roots embedded deep down at the base of the tap. Secondly, the soil itself could be naturally rich in minerals, or may have some components that add to the healing capacity of the water.

The manager also added how other people are finding ways of making money out of this water. The regular traffic of auto-rickshaws from Faisalabad, Sheikhpura, Chenab Nagar and Sargodha are selling the water beyond the price that the journey incurs, thereby earning a profit. Moreover he noted how people at times get unreasonable with their demands.

*“Once we were visited by a large tanker, much like the one that supplies water in houses. It was very difficult for us to comply with his demand, imagine if people start to come here with such large tankers, how will these other people standing in the long queues be accommodated. I told him that since he is visiting our dera and is our guest for the first time, I would not let him go empty handed, but this cannot happen again. It took us 4-5 hours to fill up his large tanker, he was taking water to Sheikhpura.*

The manager also shared that he plans to construct a veranda and a sink facility at the site so that the visitors can be comfortable. Currently, the only available shade is being provided by the *peepal* tree, and the long queues in summer can be very straining and tiresome for the patients. He intends to install these facilities before the arrival of next summer season.

Most of the respondents (registered patients at RHC 104 NB) had gallons filled with *Chak Mangla* water at their places, though few of them also stopped taking the water. It was shared by them that the water has no miraculous powers or even any mineral composition that may lead to complete cure of diabetes. The rest of the respondents shared that there is no harm in drinking plain water, and the water is safe and clean. Most of the respondents shared that they usually take the recommended drug with this water.

However, none claimed that it has cured or healed the diabetes but mostly did share that it has managed the diabetes so far (by managing they meant that no emergency or severity happened).

## 5.2. Home based remedies

It was found that most of the respondents were found to be using different home based remedies along with clinical treatment. The home based medication(s) was considered as a support/supplement treatment alongside clinical treatment for diabetes. Most of the respondents did not find any harm in consuming natural extracts of different vegetable, plants and even herbs. Most of the respondents also called it a form of *hikmat*<sup>162</sup> (wisdom) that may manage and maybe even cure the diabetes. A respondent clearly expressed it as:

*Saday daday par daday is jagah tay is jismaan day naal he rahay nain tay unhan nay ilaaj vi labh he leya si. Menoo tay is vich hikmat nazar andi aiy tay saray pindh vich har banday day kool aiy ilm seen aba seena buzargan tu anda aiy. Aaj toun ik sadi pehlay angrezi dawai nhi hondi si, ytay saday waday kiwain ilaaj karday san? Unhan nay khan peen dian chizan di taseer tay jari booti da ilm peda kita si.*

*Translation:*

*Our forefathers have lived in this environment with bodies like us and learned to medicate their problems and issues. I find wisdom in it for sure, you are not going to believe it but most of us (the villagers) learn this knowledge chest by chest and practice for good at large. There was no this much allopathic medicine about a century back, how did our forefathers survive? For sure, they had wisdom and knowledge of local plants and most above of all they learned the Taseer (efficacy) of vegetables and fruits (adherent male)*

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<sup>162</sup> Hikmat is wisdom, a traditional form of knowledge carried chest by chest in the community specific to environment and ecology.

The home based remedies are commonly known as *Totkay*<sup>163</sup> (local wisdom based tonics, therapies and food). The respondents considered the Totkay not just useful but also a chain of heritage wisdom. Not just that it was economical but also locally endorsed by the peer, family and especially the elders of the community as explained by a few respondents.

The most common *Totka* (singular for *Totkay*) shared by most of the respondents was the juice of bitter ground. A few of the respondents also stressed that it was not the juice but also the cooked form of it that may help manage the diabetes (if taken at least once a week or even more).

The respondents consuming the bitter juice use similar recipe (i.e., to extract juice of bitter ground) and nearly all of them recommended it to be consumed as first thing in the morning, though there was difference in opinion regarding the quantity to be consumed daily. A female respondent shared that though this remedy was really hard to consume (due to the bitterness) but helpful in a way that her body aches reduced and so had her headache and constant dullness. A male respondent shared that this extract is not only useful for diabetes but for many other diseases including diseases of liver, stomach and skin.

The other most used remedy was *Neem* tree leaves and the *Neem* tree *Miswak*<sup>164</sup> (teeth cleaning twig). The recipe for the *Neem* tree leaves did differ as most of them used it after leaving the leaves in the plain water overnight. A few of the respondents recommended that the powder form is more effective and easy to keep for months. It was also shared that the powder may be taken as first thing in the morning with plain water. Nearly all of

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163 Totkay: Plural for Totka is an indigenous recipe or medicine to alleviate or soothe an affliction, traditionally.

164 Miswak: a tooth-stick; a traditional, indigenous tool to clean teeth, mostly by the Muslims on the recommendation of the Prophet Muhammad (PBUH). Miswak (*Salvadora persica*) is one of the oldest known shrubs, being used by millions of people in various parts of the world as an oral hygiene tool. The reason for its wide use is not only its excellent mechanical plague-removing efficiency but also its broad range Biological properties (Acton, 2012). A *Miswak* is a branch of a certain tree used by Muslims as a natural toothbrush (Alserhan, 2016).

the respondents agreed that the daily use of *Neem*<sup>165</sup> tree *Miswak* may help reduce diabetes and also fight against the orally communicable diseases.

Another used remedy was Aloe Vera<sup>166</sup>. The respondents shared that it is commonly found in the village and the bitter liquid beneath its skin may be very helpful in managing the diabetes. A respondent shared that it may be best used as first thing in the morning. Another respondent expressed that the liquid like Aloe vera may be gulped with plain water.

Most of the respondents found the Totkay very useful and considered them harmless. A female respondent mentioned that:

*Aiy tak sara qudarti mamla aiy tay is da koi nuqsaan nhi. Mein apnay wastay karelay tay kawar gandal istimal karni aan tay aiy sugar da ilaaj aiy. Menoo tay aiy totkay dawai toun ziada faida denday nay.*

Translation:

This is all natural and there is no harm in it at all. I use Aloe Vera and also Bitter ground to cure myself from diabetes. I find the efficacy of these Totkay greater than the allopathic medicine. (Adherent female)

A male respondent shared that these Totkay are easy to comprehend and manage. Also that these *Totkay* are not too costly and most of them are found in the shape of plants. He further added that these *Totkay* actually supplement and support the clinical treatment and medication. According to him it boosts the allopathic medication. Another male respondent stated that since Nature is God made and the other interventions are man-

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165 *Azadirachta indica* (commonly known as neem, nimtree and Indian lilac) is a tree in the mahogany family Meliaceae. It is one of two species in the genus *Azadirachta*, and is native to the subcontinent.

166 Aloe vera grows wild in tropical climates around the world and is cultivated for agricultural and medicinal uses. Aloe is also used for decorative purposes and grows successfully indoors as a potted plant.

made that may be flawed. He also emphasized that the religious use of these *Totkay* not only help but has the powers to actually cure the disease.

*Gurh Mar Booti* (a local term for a naturally grown plant) was also reported by some of the respondents. The name of the herb “*Gurh Mar*” are made up of two letters *Gurh* (Sugar, Sweet) and *Mar* (killer, fighter, hunter). The herb was considered to fight the sugar within (mostly considered to maintain the sugar).

A female respondent (along with the female key informant) took the researcher to a nearby field, where on the corner line was found the above mentioned *booti*<sup>167</sup> (see Fig 12 below). The *booti* was often used in the morning (as first thing in the morning). The *booti* was boiled every night just like green tea (the *booti* was stained), and the *booti* water was used.

It was interestingly found that a few of the respondents also added sugar in the *booti* water as expressed by a female respondent (who took the researcher to pluck *Gurh Mar* from the nearby fields) as:

*Meri nand nay menoo Gurh Mar booti da nuskha dasya sit ay chaar toun panj mahinay istimal karan da kheya si. Mein pelian day naal toun toor leni aan ya kisi noun kehni aan kay leya devay. Menoo bay zaiqa lagdi si booti tay fair mein cheeni pa kay peeni aan. Nand nu pochya si toun nay vi hasdyan mana nhi kita si.*

Translation:

My sister in law told me to use the *Gurh Mar* with a specific recipe for at least four to five months. I pluck it from nearby fields or ask any of the family members to fetch it for me. I found it tasteless, so I started adding sugar to it. I

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167 *Booti*: herbs, shrubs, plants used for cooking and medicinal purposes in the indigenous culture of Pakistan, such as mint or *podina*, coriander or *hara dhaniya*, which are also used for relieving stomach aches and other related issues.

also confirmed it from sister in law. She smilingly allowed to have a hint of sugar in it. (Adherent female)

Other respondents (who used the booti) also confirmed the best use of it early in the morning (as first thing). The respondents called it in local term as:

Statement:

*Nirnay tidh (Gurh Mar peeni ai)*

Translation:

Have it as first thing in the morning (on empty stomach)

Statement:

*Swaray khali tidh peeni ai*

Translation:

Have it on empty stomach in the morning

Figure 12 Image of Gurh Mar Booti



### **5.3. *Hakeem* (Traditional Herbalist)**

Most of the non-adherent patients' were found to be relying on the alternate treatment package offered by local *Hakeem* for diabetes. According to the non-adherent respondents, *Hakeem* is well revered personality and is often considered as a man of wisdom in other important worldly and religious matters (but may not be confused with a specialized holy man).

Most of the non-adherent patients visited *Hakeem* as their priority alternate option for the management rather cure of diabetes. The respondents shared that the medications and treatment offered by *Hakeem* has a long valid history and also hold an authentic background. A male respondent explicitly shared that:



*Raatan raat koi hakeem nhi banda, meray hakeem sahib da taluq hakimian day khandan naal aiy tay unhan nay hikmay apay walid sahib toun lai sit ay unhan nay apnay walid bazurg toun lai si. Mein unhan nu jadi pushti janda haan taan kar kay unhan day mashwaray, dawai tay tariq e ilaaj tay bara bharoosa aiy.*

Translation:

One cannot be a *Hakeem* overnight, the *Hakeem* I am visiting has a family background of *Hakeems* and he learned and practiced it with his father and his father used to practice with his grandfather. I know his family and his background that is exactly why I rely on his opinion, medication and treatment methodology. (Non-adherent male)

It was found that the treatment offered by the *Hakeem* was more costly as compared to the public health facility but the patients were mentally satisfied by the treatment and medication given by the *Hakeem*. A respondent shared that the *Hakeem* lives in the community and he does visit the patient free of cost and also adjusted the fee keeping in view the financial background and situation of the patient. A female respondent shared that she trusted *Hakeem* for the treatment he suggested for her diabetes. Another female respondent expressed that:

*Hakeem sahib di diti khorak day naal mera namaz roza behtar ho gya aiy, hun tay thoray rozay vi rakh lena. Pehlan tay sorat e haal theek nhi si. Agay tay mein awazar rehnda si par hun wazu namaz tay ghar day kam kaaj wastay nas bhaj kar lena.*

Translation:

I am able to fulfill my daily religious obligations after the treatment and medicine given by *Hakeem*. I was also fasting for a few days during the holy month of Ramadan. My religious life was compromised before this treatment. I was lethargic and had to visit the toilet frequently but now consider myself fit for religious obligations and house chores. (Non-adherent female)

According to a female respondent, *Hakeem* gave her maximum time and listened to her problems and issues in detail. She further added that instead of prescribing exercise and diet, she was given proper medicine that especially attacked her body aches and dullness.

A male respondent shared that a message may be left if *Hakeem* was not available at any visit because his clinic is in his house. The family members of his family were also very kind and made sure that no patient was left unheard. He further added that *Hakeem* would always contact back.

#### **5.4. *Baba Dam Wala* (Holy man - Spiritual treatment)**

A few of the respondents shared that the diabetes diagnosed to them was after an emotional episode that traumatized them. It was found that the death of a closed relative triggered the diabetes as per the perception of a few respondents. A female respondent burdened her cause of diabetes due to the exploitative relationship with her partner that ended up on/as a divorce. She further added that she was under the spell of an evil eye that caused the poor relationship, divorce and finally suffering (in the form of diabetes).

It was found that these respondents considered diabetes as disturbance in the spirit and emotions of oneself instead of the body itself. Respondents did share that the symptoms of having headache, dullness, lethargic, frequent urination and especially body aches were related to black magic in specific or evil eye in general.

##### **5.4.1. Divorced in the name of Sugar**

*Kulsoom bibi* was born and raised in village 104 NB. She was not able to complete her secondary education but did her primary education from the public girls' school in the village. She was married for 12 years and she was unable to conceive for first few years that stressed her immensely high all the time. Within a year and a half, she was diagnosed with diabetes after her complaints about blurry vision, aches and dullness. Initially she was taken to the local dispenser by her mother in law. The dispenser suggested her to visit the RHC for further investigation. She had poor relationship with her partner who would even get angry on small things and would rant her that she is an incomplete

woman as she is unable to conceive in these many years. After being labelled as diabetic, she was initially sent back to her parents' home. She was told by her in-laws that this relationship may end. The general perception regarding diabetes (commonly known as sugar) also included infertility as a consequence of diabetes for both, male and female. Kulsoom felt grieved and saddened since she had moved to her parents' house as the resources for her treatment were not just scarce, but the divorce had left her in a position where she was not able to demand anything extra from her parents, her accompanying brother, and his wife and children. She heard about the *Baba Gee* who is not just a holy man, but cure diabetics with a blessed sugar (given to the patients in small sachets to be taken thrice a day). She also heard that the *Baba Gee* may not take fee from the poor people. She found this as the most relevant option to treat her diabetes and sufferings, since the allopathic treatment required monthly follow up that may consume a working day and travel cost every month. She is now getting treated by the *Baba Gee* free of cost as she was initially given sugar for a few weeks along with a dam that may be repeated when required. The *Baba Gee* claimed to fully cure her if she keeps on having the blessed sugar on the said timing(s) and routine dam. Since *Baba Gee* can be approached by a 20 minutes' walk instead of RHC that is few kilometers away, it made *Kulsoom* to independently visit him and get herself cured. She does not find the treatment helpful for now, but for her, this is the only feasible option she is left with. She was though satisfied regarding the dam<sup>168</sup> she receives on every visit from *Baba Gee* as it relieved her stress, fears and even aches.

It was found that respondents from financially poor background did use the option of spiritual treatment as the feasible and only option. All of the non-adherent patients getting treated spiritually are female, and were found to have less voice in the domestic decisions.

It was found that the respondents under spiritual treatment also seek other options more actively as compared to other treatments mentioned above. Other than the case study

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168 Dam is to recite (silently and explicitly) the holy words from the divine scriptures and blow it on the patients or devotees.

mentioned above, the non-adherent female respondents mixed spiritual treatment with home based remedies and seeking visit to the traditional herbalist. It was also found that the respondents using spiritual treatment were less social and relied less on the peer group advice.

## **5.5. Factors affecting the adherence to the clinical treatment**

The clinical treatment (i.e., follow up visits for drugs and examination) was found to be influenced by the perception towards the public health service delivery, opportunity cost that may hinder the commute, and adherence to the follow up visits. The perception of curability of the disease greatly inclined the respondents to seek help from other methods available within their range. The understanding of getting cured or having maximum benefits was found to be of great importance as compared to managing it for the rest of the life. The gender was also found to be an important factor that may influence the adherence to the clinical treatment in specific.

### **5.5.1. Perception towards public health service delivery**

It was found that the general perception of the respondents towards the primary health care service delivery was not satisfactory. The respondents shared different problems and issues faced by them during their visit and follow up.

It was shared that the interpersonal communication at RHC is low (especially the physician) in a way that the patients were unable to discuss their fears and problems in detail. A male respondent shared that the prime job of a physician is to satisfy by engaging in a little discussion regarding the issue. It was further added that it would greatly help in winning the trust and confidence of the patient. An elderly female respondent expressed it as:

*Vekho! Mein budhi aan tay rickshaw tay apnay putar tay noo naal tarkay tay ai aan. Lamian qataran nay tay haal bura kita aiy tay agay waqt vi pora nhi labhya. Mein doctor sahib toun sawal puchnay si par unhan nay jaldi naal check kar kay chothay doctor kool bhej dita, unhan agay he baray mareez bethay san.*

Translation:

Look! I am old and I came on a motor rickshaw with my son and daughter in law since early morning. The long queues are so hectic, and at my turn, I was not even given proper time. I wanted to ask number of questions from the doctor, but he only checked me quickly and prescribed, and sent me to the paramedic who was already sitting under the flock of patients. (Non-adherent female)

Another female respondent shared a similar experience where she had to wait for almost an hour for her turn to arrive, and was given a few minutes with the doctor. She further sensibly added that:

*Menoo pata aiy kay hoor vi mareez apni wari tay bethay nay. Doctor sahib day kool har sawal wastay aiy dua hondi aiy kay Allah khair karay ga. Tay chothay doctor sahib jadoon dasan chakar lao.*

Translation:

I understand that a lot of other patient were in the queue and waiting for their respective turns. The doctor had one answer for my every query that you will be fine with the grace of God and you may visit us when told by the paramedic (adherent female)

A male respondent said that, best is to come before the RHC start operating in the morning. He further added that he came early to become an early bird for the turn. He expressed that:

*Mein apnay lagay mareezan naal salam dua rakhna tay koshish hondi aiy kay kisi sugar day mareez naal gal baat ho jaiy takay ik dojay toun sikhiay. Is tarah wari da intizar karna asan ho janda aiy tay naal ilm vi hasil honda aiy.dosray mareezan day naal dawaian tay maslian tay gaal baat naal ilm hasil honda aiy.*

Translation:

I interact with other patients who are from my community, but I also make acquaintances with other patients. I try to find another diabetic so that we may share our experiences. By that way, the waiting becomes easier and healthier. I try to tally my prescription with the other diabetic(s) and also share the problems I suffer due to it, and try to learn the same from the other end. (Adherent male)

Most of the respondents did share their grievance of inconvenience, especially the elderly patients, who complained explicitly about the wait for the turn, sitting space, poor toilet facility, energy cut down and humidity, especially in peak summers.

The other important point raised by nearly all of the respondents was the quality of the service, especially their perception about the quality of the diagnosis, prescription and funneling it down to the drugs provided. The respondents also mentioned that the distribution of drugs was also confusing, at times the patients and also the accompanying family members were unable to understand the prescribed frequency, and have reported to have taken less or extra frequency, and also got confused between the two drugs. A male respondent shared that the distribution of the medicine may be stapled with at least a satisfactory briefing about it by the paramedic. Another male respondent shared that it is his personal contact that he was able to understand and also called paramedic telephonically in case of confusion.

The perception of the patients (and also of their family members and peer group) played an important role towards adherence and non-adherence. The overall communication skill(s) at the public health facility was generally complained (as less responsive and inactive, especially in the case of physician) by the patients, and also by the accompanied family members. The morning timing(s) of the RHC also contributed greatly towards non-adherence and a pull factor towards private clinics and also other available options (supplement treatment/alternate treatment) in and around the community. The role of paramedic, however, was considered helpful, and has the potential to further help patients towards adherence of the proposed treatment. The paramedic, due to his designation of counseling the patients (actually made him closer to the patients). The paramedic (if active) may improve the follow up visits and counseling sessions in each of the visits.

The paramedic was also found helpful in answering to certain problematic questions regarding the proposed lifestyle change. The answers were given in local terms and the suggestions were also found to be delivered keeping in the view, the context of the village life.

### **5.5.2. Opportunity cost**

Most of the male respondents found visit to the RHC as equivalent to one daily wage (especially for daily wagers). It was also found that the female respondents paid opportunity cost for a single visit to the RHC (especially in case of house chores).

An adherent male respondent shared that his monthly budget got upset since his diagnosis at the same RHC. He further added, that he got convinced regarding the lifelong management of diabetes after various consultations with the friends, paramedic (of RHC 104 NB) and the doctor (both of RHC 104 NB and DHQ Sargodha), and thus requires financial management with it. He expressed it as:

*Mein ik sarkari idaray tu apni mulazmat puri kiti aiy tay hun mein apnay pind vich rehna aan. Mera ik putar aiy tay dhian da viyah ho chukya aiy. Mein kala he hun apni pailian tay zaminan da khyaal rakhna. Har chakar tay baqi kam ruk janday nay tay taan kar kay mein ik private hospital noo vikhana shoro kita kyun kay unhan da hospital shaami chalda aiy. Paramedic nay menoo samjhaya kay sarkari hospital sasta vi aiy tay acha vi aiy tak har maslay da ilaaj kar sakda aiy.*

Translation:

I am retired from a public institute, and since my retirement, I have moved in my village with my family. I have only one son and he lives in the city, and my daughters are married. I am the only one who takes care of the farm and lands we have in the village; I pay opportunity cost for each day I visit RHC. Initially I thought of getting the treatment from a private clinic since it operates in the evening, but the paramedic has not only convinced me, but ensured that the public

setup is more equipped and has strong referral mechanism(s) in case of any emergency or complication. (Adherent male)

A male non-adherent respondent shared that he is the only bread earner of his house, and runs a vegetables and fruits selling shop in the vicinity. He stated that it is not a big setup and it requires a daily management of buying, selling, sorting and storing vegetables and fruits. He further stated that:

*Meno apni sugar da pata RHC 104 Shumali tu laga si par mein hun dawai lain nhi janda kyun kay dukan band karni pay jandi aiy. Jay adhay din vi dukan band rakhiay tay ghar da chulha band honda aiy. Meray kool koi mulazim vi nhi kyun kay meri dukan chothi hai tay udha kharcha pani nhi nikal sakda.*

Translation:

Although I got diagnosed by the RHC 104 NB, I was unable to remain regular for the follow up visits as I had to shut down my shop (on the day of visit). A half day visit costed me a lot, and also disturbed my entire routine management. I don't have any helper as it is a small setup, and cannot afford additional finances for it. (Non-adherent male)

A female non-adherent respondent shared how visit to RHC implied an opportunity cost for her and also for the other family members. She expressed that her daughter had to take a day off from her school so she may manage the house chores and take care of her younger siblings. Her partner also had to take a day off from the work.

It was found that non-adherence was not just a derivative of opportunity cost alone, but also of the direct cost, majorly influenced by the travel cost as most of the respondents live in the peripheral zones of the village. The opportunity cost was also found to be a major reason that forced the respondents to opt for the private practitioners, and also to find the supplement or alternate treatment(s). The travel cost was also found to be a significant reason towards non-adherent behavior. Most of the respondents hired a local motor rickshaw for the visit (hired for the entire visit i.e., pick, wait outside the RHC and



drop). A few of the male respondents did use the motorbike, while some also used the public transport, and also their donkey cart.

A non-adherent female respondent was accompanied by her husband (who owns a donkey cart). She shared that her husband had to take a day off for the visit to RHC. She also added that her daily house chores and responsibilities were compromised. Though the checkup and drugs are for free but the travel and opportunity cost did play an impactful role towards non-adherence.

An adherent female respondent shared that her son was very helpful in her diagnosis and monthly checkups. She further expressed that her son hired the services of a man for his farm business so he may take care of her (including daily glucose check and blood pressure monitoring) and further investigations when required. She shared that her son dedicated a motorbike for her as well.

A male respondent shared that the public transport charged according to the distance travelled (the public transport charged it as per stop overs/stations). It was also shared that the public transport not only charge fare but also consumed time (the wait may reach up to half an hour at times).

In both cases (adherence and non-adherence) was influenced by the affordability, both, in terms of opportunity cost and travel cost. The follow up visit was directly influenced by if a patient or a family member had a conveyance and domestic support (especially in case of females for house chores and responsibilities). The direct cost on the other hand included the fuel price (in case of motorbike), fare rate (in case of hiring a motor rickshaw), and fare (in case of any public transport).

### **5.5.3. Perception of curability of diabetes**

Most of the respondents considered diabetes as a curable disease. It was found that the female respondents in particular were explicit about the curability of diabetes. A few of the female respondents also related diabetes with weakness and dullness, and did not consider it as a permanent disease; hence, the sick role was different in different cases.

A female respondent expressed that:

*Mein Chaudhry Sahib di haveli vich mulazim aan tay unhan nay he ik dhara sanoo rehan wastay dita aiy. Pehlay menoo chakar anday si tay naal latan vich bara he dard si kaas toor tay pinian vich. Mein rati doodh peena shoro kar dita kyun kay khana pakana, dhona tay safai meray sir tay vay. Thoray haftian vich meray kolon tarkay jag he nhi honda sit ay poray jism vich dard si. Meray banday nay Chaudhry Sahib toun chuthi lai takay hospital toun check karwa sakiay. Oo hafta bas mein chthi kiti tay manji tay pai aan, hun menoo zara aram aiy tak naal asi Hakeem sahib noo vikhaya tay kujh haftian vich mukamal aram a jaiy ga.*

Translation:

I work for *Chaudhary Sahib* at his *Haveli*, and live (with the family) in the quarters in the backyard of the *Haveli*. Initially, I had head spinning and aches in my both legs, especially calves. I started taking milk in the night before going to sleep as I wake up early, to perform house chores before going to *Chaudhry sahib's* house for washing, cleaning and cooking at times. Within a few weeks, I was not able to wake up early and my body aches triggered. This was the time when my husband decided to request *Chaudhry sahib* for a few days off so I may visit the RHC. This was the only time when I permanently adopted the sick role. I don't consider myself permanently sick since the diagnosis and initial medication. Now I have started the treatment prescribed by the *Hakeem sahib*, and will get rid of my diabetes in a few weeks.

Another female respondent shared that her sister in law did use the *Chak Mangla* water for her diabetes. According to the respondent, her sister in law was diagnosed a year back. She further added, that though she got diagnosed by an allopathic doctor, but she got cured by the *Chak Mangla* water and the home based remedies (especially the

*karela*<sup>169</sup> juice). She stated that she is on the same route to cure her diabetes, and managing it with the Chak Mangla water and different home based remedies.

A male respondent shared that he believes that diabetes is a curable disease, though it affected the life in a way that his religious life is compromised, especially in keeping the ablution for the daily prayers (especially in winters). He further shared that:

*Menoo rozay dekh bhaal kay rkhan da keha gya sit ay menoo bari pareshani si. Baar baar peshab toun namaz wazu da vi masla si. Mein Chak mangla da pani tay dam darood vi karwaya aiy par Hakeem sahib nay asal ilaaj kita aiy. Baqi ilaaj totkian day naal kar rhian tay jald he bilkul theek ho javan ga.*

Translation:

I was requested to remain careful in terms of fasting in the holy month. I was so worried about my religious obligations. The frequent urination had already made my travel for farm business restricted. I kept myself alert to cure my diabetes; I did try *Chak Mangla* water, and also received dam for the same issue as a spiritual treatment, but finally the treatment from the *Hakeem* turned out successful. I am only on *Totkay* since a few weeks, and I am treating it symptomatically. This means that the diabetes is gone, and the aftershocks are getting managed with the home based treatments. (Non-adherent male)

A female respondent shared that the diabetes had pushed her divorce, though the relationship with her partner was never as strong. Diabetes is commonly attached with infertility (in the community), though it can be cured as stated by her. She further expressed that:

*Menoo aulad nhi hoi shadi toun aaj tak...tay agay aiy sugar vi ho gai aiy. Menoo pata hai kay sugar tay aulad donan da ilaaj mumkin aiy. Mein rohani ilaaj shoro kita aiy tay dam vali cheeni vi lai aiy tay dam vi karwani aan.*

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169 Karela: Bitter ground

Translation:

I was not able to conceive since my marriage..., and then the label of diabetes. I am sure that both my diabetes and infertility can be cured. I have started taking the spiritual treatment (blessed sugar) and routine dam. (Non-adherent female)

It was found that the perception of and towards the curability of diabetes helped the registered patients to explore options other than the allopathic clinical treatment. It was also found that the word of mouth regarding other options appeared as strong claims to cure diabetes, and may bring maximum benefits. Most of the respondents shared how they have heard about the *Chak Mangla* water from the peer group(s) that may be taken for a few months to cure diabetes. Also, different advertising banners (especially in the Sargodha city) by *Hakeem* and Holy man attracted different patients.

Figure 13 Image of Advertisement



Note: The advertisement saying capsule for Diabetes (commonly known as Sugar)

#### **5.5.4. Gender**

The adherence to the clinical treatment was also influenced by the gender of the patient. The male respondents did enjoy more liberty in the process of getting diagnosed, taking multiple opinions, and also visiting and exploring other treatments. The female respondents relied mostly on the opinion of the head of the house (in the female patient is the wife of the head of the house or a subordinate); on the suggestion(s) of son (in case of an elderly widow). Female respondents were found to be dependent of male family members in terms of their mobility and finances required.

It was also found that a few female respondents did make an informal peer group (not necessarily diabetics but suffering from other diseases), belonging from the same religious sect and ethnic group. It helped them to discuss and take home opinions to further explore with the help of male family members.

The gender of the patient did influence the process of diagnosis and also the follow up visit(s). The gender was also found influential in pursuing and exploring other treatments for the cure and management of diabetes. The female respondents did rely to be escorted by the male family members in case of visiting RHC, and also to visit the private practitioners. It was also found that a few female respondents were also escorted by the elderly female family member (mother in law in most cases), especially in case of exploring treatments other than allopathy.

Tabulated summary of experience of adherence to clinical treatment and follow-up

<b>Adherence</b>	<b>Experience of adherence to clinical treatment and follow up</b>			
	<b>Education</b>	<b>Exposure</b>	<b>Finances</b>	<b>Trust on the public health facility</b>
<b>Male</b>	The education did influence the male adherents (especially towards the follow-up)	The exposure of the male patients especially who worked as a public servant in different public institutes	Mostly retired public servants and financially stable patients remained adherent	Trust on public health facility was also an important factor towards the adherence
<b>Female</b>	The education of the treatment supporter and family did ply an influential role in contributing to the adherence (of follow-up)	The exposure of the treatment supporter (especially the head of the family) in the adherence of female patients e.g., having the experience and exposure of working internationally and in cities	The family support especially the treatment supporter (mostly son in case of mother) made female to remain adherent	Trust on public health facility was also an important factor towards the adherence
<b>Common Factors</b>	Education (of the patients) allowed the paramedic to	The exposure allowed to understand the need	Finances played a major role	Perceptions towards public health

	convince and motivate for the follow-up visits	and adherence to the follow-up visits	in achieving the protocol of adherence	service delivery
<b>Non-adherence</b>	<b>Experience of adherence to clinical treatment and follow up</b>			
	<b>Support/Supplement treatment</b>	<b>Support/Supplement treatment (Home based remedies)</b>	<b>Alternate Treatment (Herbalist – Hakeem)</b>	<b>Alternate Treatment (Spiritual healing)</b>
<b>Male</b>	This treatment helped male patients to rely both in terms of using the <i>Chak Mangla</i> water as alternate and supplement treatment (especially in case of taking opinion and treatment from the private practitioner).	Home based remedies were found to be learned generation by generation especially learning about the effectivity of the vegetables, plants, fruits and other food items.	Trust on Hakeem and having faith in the traditional knowledge on achieving the maximum benefit(s). It may cost same or even more but the trust on Hakeem is at times considered to be traditionally appropriate.	Spiritual treatment was used as an ongoing treatment by the patients and it mostly supplemented the other mentioned treatment options.
<b>Female</b>	The water of this	Female patients	Females	Spiritual

	<p><i>dera</i> is considered as maximum benefit or even may cure. The female patients relied on their treatment supporter to get the water for the respective patients.</p>	<p>used different combinations of food and also took opinion from the peer and elders. Long term management and benefits were perceived.</p>	<p>also rely on the opinion(s) of Hakeem regarding their physical conditions and problems. Hakeem offer such treatment methods that are easy to comprehend and locally available.</p>	<p>treatment is endorsed in terms of domestic understanding. Acceptability in the family members. Access Low cost</p>
<b>Common Factors</b>	<p><i>Chak Mangla</i> water is revered apart from the <i>dera</i> owned by the sect that are considered as non-Muslims (<i>Ahmadi</i>) Maximum benefit or cure Low cost Easy to use Simple treatment,</p>	<p>Easy to comprehend Domestically acceptable and available Easy to manage</p>	<p>Traditional bonds Respect for Hakeem Hakeem's treatment is often considered as having low or no side effects</p>	<p>Accessible Low cost Easy to understand as most of the treatment is driven by the treatment offer. The patient takes back home</p>



	less complexity		at all.	blessings instead of medications. Spiritual treatment also requires follow-up.
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The table above was designed to summarize the experience and perception of already mentioned categories of registered patients regarding adherence towards clinical treatment and issues that may influence the follow-up. The experience of adherence to clinical treatment and follow up is further divided into four sub-categories including education, exposure, finances and trust on the public health facility for adherent patients.

The non-adherence is influenced on the other hand by four sub-categories including support/supplement treatment (especially the *Chak Mangla* water), home based remedies, herbalist (*Hakeem*) and spiritual healing.

The adherence was found to be influenced by the education of the patient or the treatment supporter of the patient (especially in case of female patients). The finances also played an important role to overcome the opportunity cost.

## 6. EXPERIENCE OF LIFESTYLE CHANGE

The lifestyle modification counseling included change in diet, daily exercise and smoking cessation. It was found that the counseling session was delivered by the paramedic to each registered patient diagnosed as diabetic. The paramedic also noted the basic investigation(s) on the non-communicable disease card that included fasting blood glucose, random blood glucose, blood pressure, weight, height and age, so that the achievement (targets) may be assessed on each follow up visit.

The paramedic used a pictorial tool (flip tool) to counsel the patients for life style modification. The pictorial tool included various messages ranging from the basic awareness, management, diet and exercise of/for diabetes. A separate pictorial tool was used for the smoking cessation.

It was found that the patients' counseling session took around 10 to 15 minutes for the first time (for both flip tools), but the counseling session time varied from patient to patient on follow up visit(s) due to the discussion on issue(s) like diet, sugar intake, exercise timing and space. The paramedic did provide local solutions to the above mentioned.

It was found that the adherent patients (both male and female) did discuss the issues and problems regarding the suggested lifestyle modification on their respective follow up visits. On the other hand, nearly half of the registered patients were found to be non-adherent towards the suggested lifestyle change. The decision of *Handi*<sup>170</sup> (daily meals) was found to be a major factor affecting the healthy diet (especially in case of a female diabetic). The exercise was also found to be an issue for both male and female patients, but majorly affected the females (in terms of timings and required space). The management of the diabetes in general, and management of feet (of diabetics) in

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170 Handi: a cooking utensil in traditional Pakistani culture, made up of metal or clay. Handi is also known as food (that is prepared daily in the form of gravy or rice dishes).

particular was found to be culturally interpreted and less in the clinical language and logic.

## 6.1. Diet

It was found that all of the registered patients were counseled to take healthy diet through flip tool messages that included less salt intake (per meal), less oil intake (per meal and per item), more intake of fresh and healthily cooked vegetables (daily), seasonal fruits intake (daily), pulses/lentils (daily), and to have a balanced ratio of wheat, dairy products, meat and dry fruits.

The respondents were also counseled on beverages briefly, though it raised certain queries afterwards as the locale bear the summer heat and humidity at long stretch forcing the residents to take local *sharbat*<sup>171</sup>, *lassi*<sup>172</sup>, soft drinks and cold milk with meals or even without any meal.

Most of the respondents did understand the importance of balanced diet, but interpreted it individually or as per the respective position and situation in the family. The male respondents did enjoy more authority in granting the permission and also finances for the separate healthy balanced *Handi*. Other than a few cases, most of the female respondents used other tactics to balance their respective diet that included taking a small portion of

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171 Sharbat is a local beverage in Pakistan's culture, usually made on festive occasions, or in summers to have a taste of chilled drink on a hot day. It is usually sweet, prepared from the combination of the essence or extract of a flower or a plant with sugar, and artificial food colors in some cases. Sherbet can be a medicinal drink, a syrup or juice concentrated to a certain degree of viscosity. Sugar or honey is usually added to it in order to thicken and sweeten it. Nizami describes the sharbat as "cold and sweet" (Ruyembeke, 2007).

172 Lassi: a local, indigenous drink made from adding yoghurt to milk. It can be both sweet and sour, depending upon the quantity of sugar added. Lassi is a summer drink, with a frothy texture. But the form in which it is most cherished and unbeatably popular in probably the homes of all the millions who constitute the Punjab is called *lassi*: the sweet or salty summer yoghurt drink that is traditionally served to cool people down as they enter a home to escape the burning blistering sun in rural Punjab. Punjabis restrict to drink *lassi* during their winter season (of temperatures that would prevent it from qualifying as "winter" by peoples of more northern climes). It is their best-loved summer drink, a balm for the healthy as well as those suffering the agonies of sunstrokes (Semali & Kincheloe, 2011).

the curry aside before putting or adding the required oil and salt in it. Few female respondents also managed it in a way that they cut down the quantity of curry and bread in daily meals. Elderly female (usually accompanied by/with a son) enjoyed more liberty in having the suggested balanced diet. A few of the male respondents also shared that though *Handi* was financed by them as the head of the house, but it was managed independent of them. It was also shared that a few of the male respondents did cut down the number of *chapati*<sup>173</sup> and the quantity of the curry. A male respondent shared it as:

*Pehlay mein roz chopri roti khanda sit ay hun jadoon toun sugar da pata chalya  
aiy tay mein sab toun pehlan suki roti tay a gyan takay sugar control kiti ja sakay.*

Translation:

I used to take *chopri*<sup>174</sup> roti (chapatti with ghee) in my every meal, but since my diagnosis I have stopped taking the ghee on my chapatti as my first step towards the management of my daily diet. (Adherent male)

A female respondent shared that it is nearly impossible to cook a separate balanced *handi* for herself. She further added that only one *handi* is cooked (and how can she make it separate for herself). She expressed it as:

*Mein wakhri handi tay nhi bana sakdi. Mera banda, bachay tay meri saas ik he  
handi vichon khanday nay.*

Translation:

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173 Chapati, also known as roti, safati, shabaati and roshi, is an unleavened flatbread.

174 Chopri Roti: Chopri Roti is an indigenous food, which is made by applying butter, or *ghee* on a traditional, wheat Roti, Chapati, or flatbread. The Roti is made by kneading wheat dough with water, and then rolled to make a round shape. After the Roti is cooked, butter or *ghee* is applied while it is still hot.

I don't have the finances to cook a separate portion for myself. My husband, sons, daughters and mother in law eats from the same handi. (Non-adherent female)

Another female respondent shared that since she is living with her parents, she cannot afford to request for a separate *handi* or even a separate portion. She explicitly stated that:

*Menoo talaag ho gai aiy tay mein roti apni Bhabhi kolon leni aan tay mein wakhri handi ya parhezi handi da kis tarak keh sakni aan. Mein tay apnay wastay koi phal sazi vi nhi khareed sakdi. Maa peo tay pai day kharchay di muhtaj aan.*

Translation:

I am a divorcee and my brother's wife takes care of the handi; I am not at all in any position to demand for a separate portion. I cannot even buy fruits or fresh vegetables as I am highly dependent on my parents and brother for the required finances. (Non-adherent female)

On the other hand, few of the respondents managed to cut down the quantity of the food intake (including curry and wheat). Some of the female respondents also managed to take the portion of the curry out before adding oil to it. The *handi* is usually financed by the head of the house (usually a male member), and enjoyed more authority (if diagnosed as a diabetic) as compared to the female respondents (different in case of an elderly widow taken care by a son).

It was found that most of the food was bought on the daily basis by the females from a local market or by the males at the end of their work (on their way to house) from a local market (to be cooked next day) as most of the respondents had no or less operative refrigerator. Head of the house usually decided for what to be cooked next day. It was found that most of the respondents did enjoy *chapatti* with mangoes (especially for the lunch) in the summers. Most of the respondents did not find mangoes as an imbalanced diet for diabetes. Most of the sweetening fruits were also considered as a fruit and not as sweet or a potential harm for their diabetes.

It was found that most of the respondents stapled diabetes with white sugar mostly (and less with brown sugar). A few of the respondents also shared in an exclamation manner that how come salt or oil or sweet mangoes be harmful in case of diabetes?

It was found that all of the respondents were taking three meals in a day along with tea, drank at different times of a day (as per the season). Most of the respondent took three meals as *nashta*<sup>175</sup> (breakfast), *din*<sup>176</sup> *di roti* (lunch) and *raat*<sup>177</sup> *da khana*<sup>178</sup> (dinner). Most of the respondents had at least two meals (breakfast and dinner) with the family members (but not necessarily together). It was also found that the diet patterns were similar for most of the respondents (with little preference).

#### **6.1.1. *Nashta* (breakfast)**

Most of the respondents did report early breakfast (mostly after the break of the dawn) after the morning (*fajar*) prayers. Most of the respondents shared that they took a *chapatti* with tea (usually sweet) as their complete breakfast. The respondents also shared that a *paratha* (with *desi ghee*) was also taken with a fried egg (salt on it), omelet egg or curd (with white or brown sugar on it) followed by a cup of tea (sweet) for a few days in a week (as a standard breakfast). The respondents also shared that the breakfast is incomplete without a cup of sweet tea. A female respondent, smiling, said that the actual meaning of tea is sweetness and it should be sweet. She also added that though she is diabetic and fond of tea (but cannot take tea without sugar any part of the day).

*Nashta* was usually made by the wife of the head of the house, or daughter in law. The breakfast was first given to the male members of the family so they may leave for their respective job(s). The breakfast was served on the *manji* (bed) in case of an elderly

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175 *Nashta*: Breakfast

176 *Din*: Day, Day light

177 *Raat*: Night

178 *Khana*: Food

family member. A male respondent shared that a complete heavy breakfast helps to fight the day (fight meaning the heat in summers and cold in winters).

The *Nashta* was considered as an important meal as stated by a female respondent:

*Nashta tagra hona chahi da aiy warna din changa nhi langda*

Translation:

Breakfast should be heavy and complete, otherwise it may hinder daily routine and tasks

A male respondent also shared that:

*Nashta na karna nahosat aiy tay nashta bhar kat karna chahi da aiy*

Translation:

To leave breakfast in the morning is like a bad omen, and one must stuff breakfast properly

### **6.1.2. *Din di roti* (lunch)**

The lunch was found to be different for different respondents. Most of the male respondents were working and had their lunch with either colleagues (sharing the food portions together) or alone. In case of having lunch alone, respondents either got the lunch made and packed (from home), or bought from a nearby small restaurant.

On the other hand, most of the female respondents had lunch at home (mostly self-cooked). A female respondent (who works for *Chaudhry sahib*) got the lunch from the handi (made at Chaudhry's home by her). This portion was part of her monthly package. In this case, she too had lunch whatever was made for the family of *Chaudhry sahib* (mostly with oil and salt).

The working male respondents had the lunch either made from home (carried in a shopping bag, *chapatti* wrapped in a cloth or lunch box in a few cases), or was daily bought from a nearby restaurant (mostly paid on weekly or monthly basis). The homemade lunch was at times shared with rest of the colleagues where the diabetics had to share and take food from the colleagues (the curry was especially shared at the time of lunch get together). A respondent shared this practice as:

*Asi daftar vich kafi arsay toun aiy karnay aan, asi saray din do roti (salan) naal lay kay anay aan tay tandoor toun rotian lenay aan. Mein hun baqian noo tay parhezi handi da nhi keh sakda tay naal beh kay ral kay khana vi penda aiy. Aiy daftar walay vi hun meray khandaan di tarah he nain.*

Translation:

It is our (colleagues) daily practice since years. We all bring lunch (i.e., curry) and get the chapatti from a nearby tandoor. The *handi* of my colleagues cannot be changed for me and I cannot leave this practice. This is my job and my colleagues are like a second family to me. (Non-adherent male)

A male respondent shared that his farm business allows him to take lunch back at home, in case if he is busy in any assignment, he orders lunch from a nearby restaurant, but rarely skips the lunch. Another male respondent shared that he buys lunch from a nearby restaurant, and the menu is limited (usually any of the two is made out of vegetables, meat or rice). He also added that the food he takes for lunch is not just oily, but also salty and spicy (he smilingly add that this might be the demand of the market, more spices more customers).



### 6.1.3. *Raat da khana* (dinner)

The dinner was usually taken after the *Maghreb* prayers (and before the *Isha*<sup>179</sup> prayers). Most of the respondents shared that the dinner was taken at home (mostly with a family member). The *handi* from the lunch is usually freshened up for the dinner or made fresh (that is half in the lunch and half freshly made for the dinner). The *chapatti* were made fresh (at home) in most of the cases. Same as the case for other dishes (i.e., rice were often made in lunch and kept for dinner). The preference changed with changing season (the use of fresh curd and lassi reduced in winters and replaced with sweet tea and sweet milk).

A male respondent shared that his dinner is incomplete without taking a tea before going to sleep. He also added that a sweet is must for him before going to sleep. He shared that he does take a few small pieces of *Gurh*<sup>180</sup> (jaggery). He also expressed a common saying that *Gurh* helps digest the food, especially dinner.

A female respondent shared that she usually takes pickles instead of curry in the dinner. She would put a few pieces of pickles and spread it over the chapatti, and considered it good for health and especially for digestion. On the other hand, a few of the respondents were also found to take *Murabba*<sup>181</sup> (especially made of carrots) in the dinner. The respondents shared that it fights the humidity, and is less acidic (to have it in the dinner).

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179 Isha: the fifth and final prayer, offered when the night darkens. The four units of the night Salah are offered about an hour and half after sunset before the bed time (Sayeed & Prakash, 2013).

180 It is a concentrated product of date, cane juice, or palm sap without separation of the molasses and crystals, and can vary from golden brown to dark brown in color.

181 Murabba: or Preserve; is a traditional 'preserve' of fruits and vegetables in traditional societies of Pakistan, such as Mango Preserve or *Aam da Murabba*, Carrot Preserve or *Gajjar da Murabba*. It is prepared by adding boiled pieces of fruits to sugar syrup, with a tinge of citric acid. Murabba, along with the significance of preserving fruits, it is traditionally considered to also have health benefits.

A female respondent shared that since her diagnosis, she has started taking salty *roti* (*missi*<sup>182</sup> *roti*) with milk lassi in the dinner. She said that it has helped to fight the weakness and being overweight. She confidently shared that she has reduced weight by not taking the curry in the dinner. She further expressed it as:

*Mein raat noo chawal tay salan lena chorh dita aiy. Hun mein ik missi riti kachi lassi day naal khani aan. Tay naal mein roti vi ghat kar diti aiy takay wazan vi theek raway. Khaan peen day parhez naal sugar control rehndi aiy.*

Translation:

I have stopped taking the curry and rice in the dinner. Now I add a hint of salt in my bread before baking it, and take it with milk lassi in the dinner. I have also cut down the quantity of my chapatti, and this all has helped me to reduce my weight. Now I manage my daily meals to cope with my diabetes. (Adherent female)

A male respondent shared that he has managed the diet (especially dinner) by cutting down the quantity of the *chapatti* and curry. He stated that he used to take two *chapatti* before the diagnosis, but now reduced it to only one in the night. He also shared that he has also stopped taking the *ghee* on *roti* as it is a common saying that the ghee lubricates the body and makes it function in a healthy manner.

#### **6.1.4. Concept of *Meetha* (sweet)**

It was found that most of the respondents did not consider sweet mangoes as sugar intake. It was shared by a male respondent that it is just a fruit:

*A fruit is a fruit, not sugary or salty as stated by a male respondent.*

It was also found that the *Murraba* was though considered *meetha*<sup>183</sup> (as it is cooked in sugar), but also healthy. The sugar was found to be the part and parcel of tea and milk,

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182 Missi: Salty, here it means salty chapatti

183 Meetha: Sweet, sugary

and most of the respondents had a very different perception about the quantity of the sugar intake as expressed by a female respondent:

*Tarkay di chaa vich cheeni da koi masla nhi. Chaa thori meetho hovay tay jism noo taqat mildi aiy. Mera tay damagh meethi chaa day naal he chalda aiy. Cheeni toun baghair chaa tay bad maza dawai di tarah aiy.*

Translation:

A tea spoon of sugar in a full cup of tea is nothing. The tea only gets mildly sweeter and provides the energy to the body. My brain start working with sweet tea. The tea without sugar is like a bad taste medicine. (Non-adherent female)

The other important finding was that the respondents considered the *meethi niaz* as healthy and blessed (especially in the form of *jalebi*, sweet rice, *halwa*, *kheer* and sweets). Few of the respondents shared that the *niaz* is like a blessing of God, and since it is distributed in the name of God, (how can it be denied or not taken when offered). The *meethi niaz* intake increased in the Islamic months of Ramadan and Muharram.

The white sugar was immediately associated as harmful *meetha*, on the other hand, a general perception was found between good *meetha* and a harmful *meetha*. The good *meetha* was normally associated with honey, *gurh*, brown sugar, *ghar*<sup>184</sup> *di meethi lassi*, *ghar day sharbat*, *meetha doodh*<sup>185</sup>, *meethi niaz*, *murraba* and sweet fruits. However the immediate perception of harmful *meetha* was also found and associated with white sugar and soft drinks.

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184 Ghar: Home, here it means home made lassi

185 Fresh milk; a white, smooth, natural drink which, in the Pakistani culture, is mostly taken from cows and goats. Milk is one of the most common articles of food throughout the world. It occupies a unique position in the maintenance of health and healing diseases. It is considered as “Nature’s most nearly perfect food.” (Bakhru, 1995). Doodh (warm milk) is locally considered to be healthy when taken with its natural cream mixed with sugar or brown sugar.

The intake of honey, hot milk (sweet) and murabba were found to be mostly used in winters (especially at the time of dinner and also with lunch). On the other hand, *meethi lassi*, *sharbat* and mango intake were found to be considerably high in summers (especially at lunch time). Respondents supported their arguments regarding the *meetha* with general wisdom and in the light of locally endorsed practices.

Meetha is also a feeling of happiness and associated with marriage ceremony, get together, and also has valuable importance in cultural customs and religious rituals. It was found that the mangoes in the summers' invites family get together. Sweets were found to be an integral part of the marriage ceremonies and other related events, including birth of a new baby. The meetha is also of great importance in certain religious ceremonies, especially in the holy months of Ramadan and Muharram.

The sweet beverages were also commonly found in the locale including *sandal*<sup>186</sup> *da sharbat*, *bazoori*<sup>187</sup>, *shakar*<sup>188</sup> *da sharbat* (also known shakar cola i.e., brown sugar cola) and other drinks with local herbal names. The common perception placed the local beverages as healthy, cleans the blood, full of energy, and fights the heat of the summers and humidity.

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186 Sandal da sharbat: Sandalwood Syrup. It has benefits for cooling down of body, kidney and liver-related problems. It is prepared by boiling sandalwood in water, and then cooking with sugar syrup. It is considered to calm the heat of the heart, body and helpful to control head spinning in summers (Ruymbeke, 2007).

187 Bazoori: The chief ingredient of Sharbat Bazoori is Beikh Kasni (*Cichorium intybus* root). Kasni roots are known as Chicory in English. It is a Sharbat of seeds. Bazer means seed and its plural is Bazoor (seeds). Because seeds are included in this formulation particularly, it is called Bazoori. Sharbat or Syrup means the sweet syrup compound, prepared from decoction, infusion, and water extract of either dry fruits or herbs or seeds etc.

188 Shakar da Sharbat: Shakar is raw, brown sugar in traditional Pakistani language. *Shakar da Sharbat* is a local indigenous, summer beverage or syrup, prepared by mixing raw, brown sugar in cold water.

The sweet sharbat (with brand names as *rooh afza*<sup>189</sup> and *jam-e-shireen*<sup>190</sup>) were also found common in use. The local *sharbats* were also poured on the ice sticks (made up of crushed ice) also known as *gola ganda*<sup>191</sup>. It was also found that the trends of offering the drinks in hospitality has changed over time. Few of the respondents shared that it was common to offer the local drinks about a decade ago, but now it is considered respectful to offer soft drinks, colas and branded juices to the guests. The intake of local sharbats and soft drinks increased at a very high rate in the holy month of Ramadan (especially used at the time of breaking the fast). A female respondent shared that:

*Sharbat toun baghair tay iftari pori nhi hon di. Rozay tay naal garmi day vich sharbat iftari welay lazmi aiy. Mein tay sarian wastay ik nikay tub vich sharbat banana aan.*

Translation:

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189 Rooh afza: Rooh Afza means ‘nourishment of the soul’. Rooh Afza is a local beverage since the Sub-Continent, which is domestically used to relieve the heat of the hot summer days. RoohAfza is a non-alcoholic concentrated squash. It was formulated by Hakeem Hafiz Abdul Majeed in 1906 in Ghaziabad, British India and is manufactured by the companies founded by him and his sons, Hamdard (Waqf) Laboratories, Pakistan and Hamdard (Wakf) Laboratories, India. Since 1948, the company has been manufacturing the product in Pakistan, India, as well as in Bangladesh. The specific Unani recipe of RoohAfza combines several ingredients popularly believed to be cooling agents, such as rose, which is used as a remedy for loo,(the hot summer winds) of India and Pakistan and Bangladesh. It is sold commercially as a syrup to flavor sherbets, cold milk drinks, ices, and cold desserts, such as the popular falooda. RoohAfza is typically and more popularly consumed by South Asian Muslims to end their fasts in the month of Ramadan, but has now seen popularity among the non-Muslim populace (Fahim, 2016).

190 Jam e Shireen: Jam e Shireen means ‘a sweet goblet’. Jam e Shireen, like RoohAfza, is also a local, herbal beverage which is usually drunk in the summers, to have a sweep of refreshment. Jam e Shireen can be prepared with both water and milk, and includes rose, sandalwood, and other herbs to give it a hint of vitality.

191 Gola Ganda: Gola Ganda is a local ice-treat for summers, prepared on carts and trolleys in the streets of Pakistan. It is prepared by grating ice, and pouring different syrups on it, including Rooh Afza, Jam e Shireen, and other flavored syrups.

The sharbat completes the iftari. The fasting in Ramadan and the heat in the summers makes a perfect combination to have sharbat at the time of breaking the fast. I make a small tub of sharbat for my entire family. (Adherent female)

The *meetha* has a significant role in most socio-cultural layers of the village. From greetings to diet and beverages, meetha is considered as a good attribute that may also be labelled with an honest and loyal person. The common saying was found as:

*Aiy banda bara meetha aiy, har kisi da khayaal karda aiy.*

Translation:

This is a very sweet person who keeps on helping and facilitating everyone around.

A male respondent shared that his friends emotionally supported him after his diagnosis and label as a diabetic in a way:

*Yaar tu meetha banda ain, taan e tenu sugar hui aiy*

Translation:

Friend! You have been diagnosed with sugar (diabetes) because you are indeed a very sweet sugary person.

The diet overall was found to be a complex socio-cultural practice, and may not be considered as a simple option that may be modified easily. Same as the case with the general perception of sweet and sugar. The adherents to the suggested diet were found to use methods as cutting down the quantity of wheat and also of the curry, and also having *chapatti* with pickles and *murraba* instead of oily and salty curry. However, the sweet tea was considered as a major factor that was not modified by any of the respondents.

## 6.2. Exercise

The lifestyle modification counseling tool suggested the diabetics to control and reduce the weight with the help of daily exercise. The respondents recalled that they were suggested to walk briskly for at least 30 minutes daily. It was found that most of the respondents were unable to adhere to the suggested exercise due to the issues of space for exercise (especially for females) and time (as when to do/perform exercise). It was also found that most of the female respondents considered house chores as daily exercise. On the other hand, most of the male respondents were found to consider going to work as a full day exercise.

The exercise was considered as a separate activity demanding a distinct time slot from the daily scheduling. The exercise was often confused with domestic physical activity (e.g., house chores) and staying operative (in case of doing a job as an employee).

The space for exercise was also found to be a significant challenge for most of the respondents. A male respondent shared that performing brisk walk was an entirely new activity keeping in view the activity/exercise culture of the village. He further expressed it as:

*Aithay walk karan wastay poray pindh vich koi jaga nhi. Menoo tay tez walk karna acha nhi lagda chahay koi na vekhda hovay. Dosra masla waqt labhan da aiy kyun kay mein koi daftri kam nhi karda. Sada kam daftari kam toun ziada aiy.*

Translation:

There is no private or walled space for doing/performing exercise in the village. I find it awkward to walk alone briskly even at a place where I go unnoticed. The other issue is to find time nearly every day for walk as I don't work for institute that follows urban office timings (i.e., 09 AM to 05 PM). My farm business timings are beyond office timings. (Non-adherent male)

The component of exercise was found hard for most of the respondents to be pursued daily, as it demanded a separate time slot (from the daily routine) and issue of space (especially for females). The exercise was found to be perceived as a sport that may be exercised/performed in the youth age bracket(s) and not in the bracket of aging. Since the village had no gym or awareness about gym, this created a very different perception towards exercise and physical activity.

### **6.2.1. Space for exercise**

The most common issue regarding daily exercise was found to be the issue of space for both the genders. The space, both domestic and public, hold and offer layers and range for both the genders differently. The males enjoyed more freedom towards mobility and dominating presence at the shared public spaces including local markets, health facilities, schools, farms, fields and shrines. On the other hand, the domestic space and morning household activities were dominated by the females (but governed in most of the cases by an elderly woman usually mother in law). The space within the household was shared by both, mother in law (dominating in most cases) and by the daughter in law (at receiving passive end). The daughter in law (as diabetic respondents) did take permission or even informed the head of the house, position of mother in law (in the absence of her husband), regarding going to the roof top (to put clothes on the washing line), buy domestic items (from a nearby local grocery store), buy vegetables or fruits (from a nearby shop) or any other related daily task(s). A female respondent shared that:

*Chahay aiy mera vi ghar aiy par mein apni saas toun ijazat leni aan kyun kay unhan di gal wadi aiy tay samjh wali vi. Mein tay apni saas noo ghusal khanay vi das kay jani aan.*

Translation:

Though it is also my house, but I must take permission from my mother in law as she has more wisdom and also better say in the domestic issues. I at least try to inform her even before going to the washroom. (Adherent female)



Most of the male respondents shared that though the village has plain terrain, but there isn't any dedicated space that may be used for the brisk walk. A few of the male respondents shared that the stream (canal) maybe used as a potential space for the daily brisk walk. A male respondent expressed it as:

*Mein pehlay nehar day naal fajreen walk karan di koshish kiti si. Tay nehar vi meray ghar toun neray nhi (kyun kay oo jaga walk wastay behtar aiy). Par mein roz roz nhi ja sakdi.*

Translation:

I initially tried going to the canal every morning after the fajar (morning) prayers for the suggested brisk walk. The canal is away from my house, though the space is obviously better as compared to any other space in the village for exercise. But I could not continue doing it daily. (Non-adherent female)

The stream was mostly dominated by the males of the village for morning relaxed walk, swimming and bathing in the afternoon (usually by children and boys). The evenings are also dominated by males by the stream. The night is usually very dark to walk by the river. Most of the public spaces were also dominated by the males. The females also visit certain public spaces escorted mostly with a male family member or with an elderly female. It was also witnessed that the females observed purdah<sup>192</sup> (not niqab<sup>193</sup> necessarily) on their respective visits to the public space(s).

It was found that only a few female respondents did daily suggested walk with the help of a peer group (made due to a common religious sect or similar ethnic background). The group did not only include diabetics, but also healthy females and patients of other chronic diseases. The group had greater mobility and strong justification to walk as a

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192 The custom, found in some Muslim and Hindu cultures, of keeping women from being seen by men they are not related to, by having them live in a separate part of the house or behind a curtain, and having them wear clothing that covers the whole body, including the face.

193 Niqab is to cover the face; veil

group (mostly by the stream and also road next to the long strip of fields). The community also endorsed females going in a group as compared to a female (walking or performing exercise).

An elderly female respondent shared that she does go out for a walk to a nearby dera (a camp like settlement near the fields). She also stated that the dera was owned by her husband, and since his death, the dera is now managed by her elder son (whom she lives with). She further expressed:

*Sadi bari zameen aiy tay naal dera vi aiy tay pelian vi. Mein tay tarkay tarkay deray day naal jani aan. Garmian vich tay bohat he acha honda aiy. Sardian vich zara masla honda aiy thand tay dhund di waja toun. Tay naal deray tay sarian nu pata aiy, othay menoo koi pareshani nhi hondi.*

Translation:

We own a reasonable area/land bisected as a dera and strip of fields. I usually go early morning for a walk by the dera and strip of fields. It is very refreshing to walk early morning especially in summers. It is at times hard for me to stay regular for walk in winters. All of the workers on the dera know my position and status, hence I don't find any issue using this space for the purpose of daily exercise. (Adherent female)

A few of the female respondents shared regarding domestic space(s) that they have used respectively, keeping in view the access, easy availability and acceptability. A female respondent shared that she has used the roof top of the house for the purpose of exercise. Another female respondent also stated that she found both rooftop and courtyard as in her access and also acceptable for the family members. She further expressed that:

*Ghar day vich walk karan di asani hondi aiy kyun kay mein har welay ghar he honi aan. Ghar di chaht tay ziada aram naal walk hondi aiy par mein sehan vich vi walk kar leni aan jay barish ya dhoop tez hovay.*

Translation:

The space within the house made it easy for me to adjust accordingly for my daily exercise. By that way, I am always present in the house and manage my exercise daily. Rooftop has better spatial dimensions for brisk walk, but I also use the courtyard in case (I get late in the morning, rain or sunlight). (Adherent female)

It was found that purdah was not a forced compulsion, but an act of choice. Most of the female respondents explained that it is their cultural practice and an honor. It was further explained that there was not any hard and fast compulsion or ruling, it was the preference of the females as well (to observe purdah and to be escorted by a male family member).

### **6.2.2. Time for exercise**

Morning walk though was not new to the respondents, both male and female were familiar and had been doing the morning walk irregularly. The morning walk was not brisk, rather a relaxed walk, and most of the respondents did find the morning walk refreshing and healthy. On the other hand, the same relaxed morning walk shifts in the evening after asar prayers in winters. The winter mornings are foggy and misty, and can be cold; for that the morning walk timings shift in the evening during winter season.

Morning walk was found to be common among the respondents who regularly go to the mosque for the fajar prayers. The time span of morning relaxed walk was not found to be more than 15 minutes. Most of the respondents also shared that the morning walk is part of commuting for prayers, and the route is from their respective houses to the nearby mosque and back to the house.

The time for exercise was hard to be found by both, male and female respondents. Most of the male respondents shared that it was not possible to find time on daily routine. Male respondents from different occupations had different justification for not performing the exercise on daily basis. It was also found that the work load and domestic life of different respondents created different priorities to seek dedicated time for the exercise. However, the male respondents did agree individually that the possible time for exercise was early

morning (some shared half an hour before and some after the fajar prayers). A male respondent expressed it as:

*Swaray tarkay koi vi warzish behtreen hondi aiy. Menoo ta yap fajreen toun baad chalna phirna tay saaf hawa da maza anada aiy.*

Translation:

Mornings are best for any physical activity. I personally enjoy getting up early every morning not just to offer the prayers, but also to inhale fresh and clean air. (Adherent male)

Another male respondent also expressed it as:

*Mera sara din faslan di rakh chak vich langhda aiy. Fajreen thora waqt honda aiy par hun mein hisaab kitaab laya aiy kay motorcycle di bajaiy tur kay pelian tak jana chahi da aiy. Mein roz do chakar la lena aan. Walk vi ho jandi aiy tay naal naal kam vi ho janda aiy.*

Translation:

My entire day is spent visiting my fields and taking care of so many things. I find early morning as the only free time slot for myself. Now I have calculated the distance of my fields from my place and I have stopped using the motorbike to commute. I walk twice in a day i.e., morning for the first visit and in the early evening for another visit. By that way, I am also adhering to the suggested exercise and taking care of my business. (Adherent male)

A few of the female respondents used both early morning (usually before *fajar* prayers) and evening time for the purpose of exercise. It was found that other than a few female respondents (one who made an informal peer group and the elderly woman with dera), mostly preferred walking within the premises of their respective houses. A female respondent explained her situation as:

*Menoo roz walk tay warzish da kheyaa aiy par mein tarkay jag kay sarian da nashta banana aan. Tay apni saas da khyaal vi bachyan tay banday noo bhej kay rakhna penda aiy. Kapray dhonay honay nay, ghar di safai tay handi vi banana hondi aiy. Menoo tay sham noo vi waqt nhi milda. Saday ghar di chaht tay sehan vich walk nhi ho sakdi.*

Translation:

I have been asked to do the daily exercise, whereas I wake up early morning to make breakfast for my husband, children and mother in law. I also take care of my elderly mother in law and make children go to school and husband to work. I wash clothes, clean my house and cook daily handi and chapatti. I hardly find time around evening to rest for a little while. The rooftop and courtyard are not spacious enough for brisk walk. (Non-adherent female)

The exercise was also found to be a complex activity keeping in view the socio-cultural settings, economic work rhythms, rural environment, and issues of space and availability of time. The exercise was also perceived and practiced differently by different respondents especially due to gender, age, access and availability.

### **6.3. Smoking**

The counseling tool for smoking cessation included five steps to quit it. It included various methods and ways to divert the smoker from smoking. The counseling session included a separate sub-session for smokers. The paramedic did ask all of the registered patients on their first visit regarding the smoking status (and even confirmed at times from the accompanying person). A few slides/messages were given to each patient (that helped to avoid passive smoking), but the detailed session were given to only regular smokers (who also volunteered to quit smoking through methods and ways described in the tool).

It was found that only two of the registered patients were found to be a regular smoker, (one male, one female). The male smoker shared that he smokes around 10 cigarettes (on

an average) per day, whereas, the female smoker was found to smoke *Hookah* (at least twice a day) made out of the home grown tobacco.

Both smokers were found to be non-adherent. The male smoker did not relate smoking cessation with the treatment of diabetes and he explicitly expressed it as:

*Menoo nhi lagda kay sugar da tay tambakoo da koi taluq aiy. Sugar da taluq tay meethay naal aiy tay tambakoo da taluq dhuvain naal. Menoo tay nhi lagda kay koi taluq aiy.*

Translation:

I don't think that the diabetes and smoking has any interlinked relationship. Diabetes is sugar related and smoking is smoke related. I don't find any connection at all. (Non-adherent male)

On the other hand, the female smoker shared that she works at the house of Chaudhry sahib and she used to make *hookah*<sup>194</sup> for him, and also freshed up the hookah after few hours as commonly known as:

*Hokkah taaza karna*

Translation:

To fresh up/refill the *hookah*

With time, she also started smoking *hookah*. She shared that she does smoke around middle of the day when she is almost done with most of the work at the house of Chaudhry sahib. She also smokes around late evening. The male smoker on the other hand shared that he smokes a cigarette post breakfast and one with the tea at his work

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194 Hookah is a single- or multi-stemmed instrument for vaporizing and smoking tobacco, whose vapor or smoke is passed through a water basin often glass based before inhalation.

station. He also smokes a cigarette each post lunch and dinner. He does smoke before going to sleep as well.

The female smoker was found to relate the smoke of hookah as natural. She further expressed it as:

*Hookah tay ghar day tambakoo naal banda aiy tay is vich kujh kharab nhi. Mein vi ziada nhi peendi, bas dopehri tay sham noo.*

Translation:

The hookah is made out of home grown tobacco and it has no chemicals in it. I don't smoke much either, just one around midday (for 10 to 15 minutes) and one around late evening (for 10 minutes).

It was also found that only two of the registered patients volunteered for the quit smoking session, but could not adhere to it. It was also found that a few of the respondents did not even accepted their status as a regular smoker in front of the paramedic and the doctor.

#### **6.4. Factors affecting the adherence to the lifestyle modification**

The lifestyle change was found to be influenced mostly by the domestic hierarchy, cultural perception of healthy diet, conceptualization of physical activity and gender. The lifestyle was found to be a complex cultural construct of traditions, religious practices and local environment.

##### **6.4.1. Position/Status in the family**

It was generally found that the position/status of the patient was significantly important and influential in trying adhering to the suggested lifestyle change. The most influential position was found to be the head of the house (that is a male in all of the registered cases households). The other important positions were of the mother and father of the head of the house. The wife of the head of the house was mildly important as the cultural perception of good wife is the one who never gets sick, ill or tired. Wife is considered

best when she bear children especially sons and also efficient in domestic chores. She must also be least demanding in terms of her health issues and problems.

The two important positions in the Punjabi domestic hierarchy may celebrate and enjoy more say and decisive weightage especially in terms of their respective health conditions. The head of the house is also found important for the family members, and his sickness may lead to haste towards diagnosis and treatment for certain reasons, including being the bread earner, protector and the marker of identity for the entire family. The mother of the head of the house is also generally considered as the pole of wisdom, source of blessings and steering wheel of the domestic economy and politics.

The positions within household were also heavily influenced by the patriarchal structure at large. It was found that a sister (for brother), daughter (for parents) may enjoy a very important role, but her status changes as soon as she gets divorced or separated. The back home sister (for brother) and daughter (for parents) may not celebrate the same old position that she once carried before getting married. The status of the elders change if any one of them passes away, especially in case of a widow. A widowed mother may have a tall standing (as carrying the status of her deceased husband).

A female respondent shared that:

*Talaaq toun baad mein apnay paikay vich vi kujh nhi keh sakdi. Mera pai ghar da khracha chalanda aiy tay mein kujh horn hi mang sakdi. Agay he meray othay aulad tay talaaq da wazan aiy. Sarian di nazar vich hun meri koi hesiat nhi.*

Translation:

Since my divorce, I have lost the say and space within my parents' home. Though my brother is the bread earner, but now I cannot demand anything extra. I was already carrying a heart wrecking title of infertility, and the divorce has added salt to my injuries. The productivity of a woman in our culture is to produce off-springs. I am also considered as non-productive for my parents and brother (non-adherent female)



An elderly female respondent shared that:

*Mera putar tay meri noo mera bara khyaal karday nain. Mera putar tay meray wastay baron machinan vi lay kay aya aiy tay naal mera wastay roz phal vi lay anda aiy. Meri noo menoo parhezi khana dendi aiy par meri larai vi hondi aiy is gal tay. Meri noo nay akhya aiy kay meray putar nay unhon kehya aiy meray parhez wastay.*

Translation:

My son and my daughter in law are at my service day and night. My son has brought me a glucometer and a blood pressure apparatus. He brings fruit for me, and my daughter in law provides me less oily and salty food, though I quarrel on this issue at times. She keeps on convincing me that she has been told by her husband to take extra care of my suggested diet. (Adherent female)

Most of the male respondents had their curry portion separated. A few of the male respondents also had a separate handi. It was also found that head of the house (as a diabetic) had better intake of fruits as compared to the wife of the head of the house (as a diabetic). The mother of the head of the house, on the other hand also had better fruit intake as a diabetic. The solid positions are clearly of the head of the house (male bread earner) and the elders especially mother of the head of the house (pole of wisdom). The other positions were found to be more liquid and remained fluid (it may solidify or liquidity may increase) keeping in view the adaptability, obedience and contribution in the domestic affairs.

#### **6.4.2. Cultural perception of healthy diet**

The diet as per the respondents may have different efficacies especially in terms of having cold or hot impact within the body. The diet was also categorized as good and bad

and also spiritual (in case of honey, *niaz*, *sehri*<sup>195</sup> and *iftari*<sup>196</sup>). The clinical understanding of diet, especially healthy diet, was found to be different from the cultural perception of healthy diet as most of the respondents shared different perceptions regarding different diet patterns, especially seasonal diet(s). The suggested diet though had less issues of affordability, and more of cognitive and cultural understanding towards different cooked food, fruits, vegetables and beverages.

The concept of meetha, as discussed above, was found to have a significant role in the daily lifestyle and especially in case of traditions and religious values. On the other hand, the efficacy of fruits, wheat, *ghee*, honey, yogurt, pickles, *chutney*<sup>197</sup>, *murraba*, vegetables and meat was found to play a very strong role in diet preferences, especially in summers and winters (and also in the holy month of Ramadan).

The concept of efficacy was found to be the major understanding towards different edibles. The major efficacies were categorized as: the strength to fight the heat of the summer, the power to heal the weakness within, the sweetness to fulfill emotions, the

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195 Sehri is the meal, or breakfast, which is made before the sunrise, and the morning prayers in the Muslim tradition, particularly in the month of Ramadan. Most common Sehri meals include some indigenous foods such as yoghurt, *parathay*, *lassi*.

196 Iftari is a post-sunset meal in the Muslim traditions, in the month of Ramadan, which marks the termination of the fast. The most common fruit eaten in *Iftar* are dates. Iftari mostly constitutes meals, such as *halwa puri*, *kachori*, fruit-chart, and beverages such as milkshakes, lemonade, and *Sharbat*. As sunset approaches at the end of a day of Ramadan fasting, Muslims prepare to break their fast with a small meal known as *iftar*. This may be accompanied with the readings from the Qur'an. Following the example set by the prophet Muhammad, eating three dates is a popular way to break the fast, after which a full *iftar* meal is consumed (Fieldhouse, 2017).

197 Chutney is a traditional, complimentary sauce often tasted with daily meals in Punjab. Chutney is smooth and viscous in its texture, and can be prepared sweet (*Meethi Chutney*), or sour (*Khatti Chutney*). Most common types of chutney include *Podinay di Chutney* or Mint Chutney, *Imli di Chutney* or Tamarind Chutney, *Aaloo Bukharay di Chutney* or Plum Chutney. Chutneys are normally made up of vinegar, sugar, salt and spices depending upon the recipe (Singh & Davidson, 2013).

energy to remain steady and fit, the juices for digestion, and heat to operate in a healthy manner especially in terms of sexual and reproductive health.

The diet was found to be a complex phenomenon where diet was not considered as something edible, but an efficacy, and may also have medicinal properties that may correct and heal the sickness of body and illness of the emotions. The handi and its decision was also found not as straight or simple, but tied in chains of positions and statuses around it, along with finances that create preferences keeping in view the domestic hierarchy.

Most of the female respondents were found to be active towards the domestic responsibilities especially towards cooking the daily food. The cooking of preferred food endorsed by the head of the house generates a reasonable status for the wife of the head of the house. A female respondent stated that:

*Mein tay apnay banday di matlab di handi roti karni aan. Meri koshish hondi aiy kay kadi vi khali tidh gharon na jaan. Achi handi menoo achi biwi tay achi maan banwadi aiy. Mein sarian di khaan peen di pasand da khyaal karni aan.*

Translation:

It is my preference to cook what my husband likes to have especially for dinner. I make sure that he never leaves empty stomach (in the morning). It is preferred to cook what everyone likes. A good handi makes me a good wife, a healthy family makes me a proud mother. (Non-adherent female)

It was found that the milk, curd and sweet *lassi* are also daily between meal items. The general perception is that such milky products fight the heat of the summers and refreshes the body functioning especially in humidity. Milk tea, milk *lassi*, curd are often used after and with the meals. Drinking milk was also a common practice. An elderly female respondent shared that:

*Menoo tay doodh bara pasand aiy. Yaqeen karo kay mein chaar liter doodh roz peeni aan. Meray walid sahib nay danger rakhay san tay meray banday kool manjhan gawan batherian nay. Mein tay roti vi meethay malai walay doodh naal khani aan. Doodh naal taqat mildi aiy.*

Translation:

I was always fond of taking plenty of milk other than my daily meals. You will not believe this, but I still take four liters of milk every day. My father had plenty of cows and buffaloes at this farm, and same as the case with my deceased husband, and now son. I often take chapatti with sweet milk (malai<sup>198</sup> wala doodh) as it energizes the body and strengthens me for daily operations. (Non-adherent female)

Most of the diet was considered with its properties and long term efficacy. The combination of different food items was also found to be an important diet practice (e.g., *chapatti* with milk, *chapatti* or rice with pickles or *chatni*, carrot *murabba* with *chapatti*, salty *katchi-lassi*<sup>199</sup> with mango etc.). Sweet tea was also an important finding as all of the respondents were fond of tea, and the daily consumption of sweet tea was at least three cups. Most of the respondents believed that the sweet tea kills the eager thirst in summers, and is a best tonic for winters.

The healthy diet was found to be an amalgamation of different cultural values (given to edibles and drinks), religious importance (edibles and drinks may carry spiritual powers to heal) and local wisdom (knowledge of the efficacy of food and its medicinal properties). The diet pattern thus, created its own wisdom and framework of being healthy, good and medicinal. Family members may learn this indigenous knowledge of the efficacy and medicinal properties from the elders (may be in extended family). This knowledge is also transmitted from chest to chest (usually girls are taught to cook in a

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198 Malai: Cream, Milkfat

199 Milky water, a small quantity of milk is added in a jug of water and is considered to fight the heat of the summers (especially in Punjab).

specific fashion by mothers and grandmothers). The boys are also told the properties (of fruits, vegetables, meat) while having food with elders, both by father and mother (and also by grandparents).

#### **6.4.3. Concept of physical activity**

Though there was not any dedicated sports ground for the youth in the village, but some young children did find space in vacant fields, unconstructed plots in a nearby colony and also in a broad street. Most of the young children were observed playing cricket, gulli danda and bantay in the above mentioned places. The bisection of the physical activity gets clearer and clearer with the age, boys start playing together more outside and girls mostly inside the house (in the courtyard mostly, and sometimes on the rooftop).

Dozens of gym were observed in Sargodha city, but there was no concept of gym (urban activity as expressed by a respondent). The concept of traditional wrestling (*pehalwani*<sup>200</sup>) and *kabaddi*<sup>201</sup> were conceptualized as healthy sports (but there was no activity for pehalwani or kabaddi found in the locale).

Most of the commuting to work places, markets and other places were usually done on motorbikes, motor rickshaw and even donkey carts. However, a decent number of people also use public transport and may also walk all the way to their respective destinations. Women would walk in the streets to buy grocery, vegetables and fruits. Children were sent to local grocery stores at times to get few things for the house.

The morning relaxed walk may be observed as early as fajr prayers. Male members of the community go to their nearby mosque, and would walk all the way and come back to

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200 Pehlwani: also known as *kushti* or traditional form of wrestling. *Pehlwani* is a traditional, folk-sport which is practiced in the rural societies of Pakistan.

201 Kabaddi is a traditional sport, mostly played in the rural areas of Pakistan especially Punjab. It is a game that would be remarkably easy to adapt to any schoolyard, since there is virtually no equipment required. Essentially, kabaddi is a well-organized game of team tag. No bats, balls, hoops, or even special shoes are required. All that is needed is a marked-out playing field that has a standardized size of 13 meters by 10 meters (roughly 43 feet by 33 feet) (Craig, 2002).

their respective houses for the breakfast. The winter season shift the walk cum get together of male members to the early evening. Elders (both male and female) may be observed in the evening relaxing and talking in the streets, and at times, outside a broad reception of a house.

The brief bisection of public and domestic space influenced the lifestyle greatly for both, men and women. The male respondents enjoyed more space, even the physical activity remained dull in case of elders. The domestic space had further hierarchies (as the mother of the head of the house may have more space within the house). The wife of the head of the house though moved freely within the house but informed the mother in law in case of going outside or at rooftop.

The divide of public and domestic was not though very concrete, but did split the responsibilities and social roles. Physical activity in terms of sports, brisk walk and exercise were considered as an urban activity as explained by a male respondent:

*Aiy shehran day lookan da tareeqa aiy, sada kam kaaj e sadi warzish aiy*

Translation:

This is like the physical activities by urban people, our job and work is our daily exercise.

The conceptualization of physical activity as suggested through counseling session was different from the normal routine in the locale. The space and timings for the exercise remained a major issue for both, male and female respondents. The female respondents considered house chores as an exercise (including cooking, washing and cleaning). The male respondents on the other hand mostly labelled exercise as incompatible with their daily work load and other domestic responsibilities.

#### **6.4.4. Gender**

The lifestyle modification was greatly influenced by the gender of the patient. The diet and exercise in particular were perceived and practiced, keeping in view the position of

the gender in the domestic hierarchy. The responsibilities and the role -in specific- assigned were found to create complexity towards the adherence of suggested diet and exercise. The gender of the patient within the household also defined the levels of adherence one can achieve.

The handi was also found to be gendered in a way of preference (what head of the house wanted to eat). The general menu for the three meals (as discussed in detail above) was also influenced by the choice of the head of the house. The elderly woman may have more space and say towards the decision of the handi. It was found that the menopause age of a female (especially in case of elderly woman in the household) was considered equal as the male gender (equal means to have liberty to exercise an initiative).

The spaces were also found to be gendered. The public as dominated by the male gender, and domestic (especially morning till evening) was mostly governed by the females (elderly woman in most cases). The more a space was visible, more it was considered as public, and a domain of the male members of the community. The walled space (e.g., house, girls' school, female wards in a health facility etc.) was considered equal as purdah.

The lifestyle overall was found to be different for both genders. The diet, especially the decision of the handi, exercise, especially the issues of purdah for female patients, and timings compatibility for the male patients were found to stimulate (both negatively and positively, mostly negative) the adherence to the suggested lifestyle change.

Tabulated summary of experience of lifestyle change

Adherence	Experience of lifestyle change			
	Diet	Exercise	Sweet/Sugar	Smoking
<b>Male</b>	Education and finances both helped (especially in case of male head of the house) to decide for prescribed and suggested change in diet.	Early morning and late afternoon walk, especially in case of visiting their fields. Walking to fields or to market instead of using bicycle or motorcycle.	Sweet is mostly considered as sugary and if taken, mostly in low/less quantity and is also often balanced with diet. Tea and <i>Lassi</i> as common drinks, adhered without adding sugar to it.	This was mostly found insignificant. Most patients did not smoke as it creates pressure on household finances.
<b>Female</b>	Keeping a small portion for themselves before adding oil in <i>Handi</i> for the rest of the family. Also cutting down on <i>Chapati</i> that helped in balancing the diet.	Female used their peer (especially in case of minority group) to walk early morning. Use of veranda and rooftop (especially early morning or after <i>Maghrib</i> )	Sweet is mostly considered as sugary and if taken, mostly in low/less quantity and is also often balanced with diet. Tea and <i>Lassi</i> as common drinks, adhered without adding sugar to it.	Insignificant in this category



<b>Common Factors</b>	Family support Education and finances Accepting the change in diet and managing it with domestic wisdom.	Acceptance of change in physical activity Managing the change through local wisdom including female making informal peer group. Creating space within home(s) in case of females. Walking instead of using motorcycles (especially to visit fields)	Balancing the cultural and religious significance of sweet/sugar in daily diet	Insignificant
<b>Non-adherence</b>	<b>Experience of lifestyle change</b>			
	<b>Diet</b>	<b>Exercise</b>	<b>Sweet/Sugar</b>	<b>Smoking</b>
<b>Male</b>	Education and finances played a great role in unable to achieve adherence. Seeking maximum benefits and cure leading to	Time becomes the constraint, especially in case daily wage laborers	White sugar is considered as more of an urban concept as compared to brown sugar Fruits are not considered as something sweet or sugary	Smoking is not mostly directly related with diabetes

	no or very less change in routine diet.		Sweets are an integral part of both summer and winter diet(s) and drinks	
<b>Female</b>	Position/status of females in the family influences the overall adherence and in specific decision of <i>Handi</i> . The domestic hierarchy of female is also influential in non-adherence in case of females.	Lack of family support House chores conceptualized as physical activity Cultural constraints such as concept of <i>Pardah</i>	White sugar is considered as more of an urban concept as compared to brown sugar Fruits are not considered as something sweet or sugary Sweets are an integral part of both summer and winter diet(s) and drinks	<i>Hukah</i> is not considered as equivalent to smoking cigarettes Smoking is not mostly directly related with diabetes
<b>Common Factors</b>	Position/status in the family plays an important role towards non-adherence Domestic hierarchy plays	Cultural concept of physical activity as equivalent to house chores Time and space for exercise are also important	Fruits, sweets and sugar are considered as distinct cultural categories	Smoking is not mostly directly related with diabetes

	an important role	common factors		
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The table above summarize the experience of or regarding the suggested lifestyle change. The lifestyle change is further divided into four sub-categories including diet, exercise, local perception of sugar/sweet and smoking. The experience of both adherents and non-adherents were documented and were tabulated separately under the above mentioned sub-categories of the main theme.

It was found that the domestic hierarchy played the most crucial role in deciding regarding or about the diet especially the decision for/of *Handi*. The time also played an important role and may be considered as a cultural category in terms of its definition and especially in relation to the gender of the patient. The concept of sugar/sweet was also found to be culturally defined and prioritized in the respective lives and lifestyle(s) of the patients.

## 7. OTHER FACTORS INFLUENCING ADHERENCE TO THE TREATMENT

This section discusses the issues overlapping the previously discussed factors as influencing adherence to the clinical treatment (i.e., drug regimen and follow-up) and lifestyle modification (i.e., diet, exercise and smoking). The factors discussed below were found to add the influence on the overall proposed diabetes care package (as effective case management).

The previously discussed factors were specific to the bisected dimension of the treatment. The clinical treatment and lifestyle change was though found to be influenced mostly by gender, domestic hierarchy, finances and perception towards curability of type 2 diabetes. The factors discussed below were found to influence the specific factors that may further add pressure towards adherence to the overall treatment.

### 7.1. Social identity of a diabetic

Most of the respondents did not know diabetes by its clinical nomenclature. It is commonly known as “Sugar”. It was observed that the support and alternate treatment(s) advertisements did not mention it as diabetes, but as sugar. It was interestingly found that the social construct of diabetes as sugar strongly inclines it with sweet intake. A male non-adherent respondent smilingly shared that:

*Menoo tay meetha ziada pasand nhi, saray ghar walay mithai, zarda, kheer tay hallway shoq naal khanday nay. Par aam mein shoq naal khana tay menoo nhi pata kay menoo sugar kis tarah hoi aiy. Meri maa do saal pehlay footh hoiy san tay meri sari zindagi pheeki ho gai aiy.*

Translation:

I was never fond of sweets though my entire family used to take a lot of sweets in the form of *mithai*<sup>202</sup>, *zarda*<sup>203</sup>, *kheer*<sup>204</sup> and *halwa*. On the other hand, I never

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202 Mithai are traditional sweets

missed a season (of mangoes). How did I develop sugar is still a mystery to me. My mother passed away two years back, and took all the sweetness of my life.

The label of being the patient of sugar is different from the clinical label of being the patient of the disease of diabetes. The label of sugar may have multiple interpretations and meanings attached to it mostly in local terms. It was interestingly found that most of the respondents associated their different conditions (self-perceived) of diabetes (sugar) as low (glucose level). The respondents in most of the conditions stated common sentences such as:

Statement:

*Aj meri sugar low ai*

Translation:

I am having low sugar today

Statement:

*Mera sar low sugar di waja tu ghum rhya ai*

Translation:

My head is spinning due to low sugar

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203 Zarda, a kind of pulao made from rice, raisins, sugar, nuts, and saffron (Albala, 2011). It is a yellowish, traditional dessert, mostly prepared on festivities in Pakistan. It can optionally be garnished with dried-fruits and sweets. *Zarda* is prepared by cooking rice in sugar syrup, and food color is added to give it a yellow coloring.

204 Kheer, a thick rice or vermicelli pudding made from boiled-down milk (*khoya*) (Albala, 2011). *Kheer* is a traditional sweet-dish of Pakistan, mostly served after meals or on festive occasions such as marriages, religious occasions like *Eid-ul-fitr* and *Eid-ul-Adha*. It is white in color, has a soft and smooth texture, and often garnished with nuts.

Statement:

*Mera dil ghabara rhya ai, sugar jo low ai*

Translation:

My heart is trembling, I have a feeling that I am having low sugar

The above mentioned sentences are socially accepted in a way that they are responded accordingly such as:

Statement:

*Jaldi naal koi meethi shay kha lo*

Translation:

Have something sweet quickly

Statement:

*Meethi cha pee lo*

Translation:

Have sweet tea please

Statement:

*Koi meethi goli taffy kha lo*

Translation:

Have some toffy please

It was also observed that disease(s) are commonly discussed in various social meetings especially in the evening(s), and also at different respective work places of the respondents. The male social circle was found to be more active in terms of seeking a coping mechanism for diabetes. Female respondents on the other hand, were found to discuss the coping mechanisms regarding the label of diabetes within one's extended family and closed community circle of females.

Most of the respondents tried coping with the new identity labeled as diabetic, commonly known as man with sugar or female with sugar. Layers of social circles were found to be active in different cases for discussing how to cope and cure the diabetes. However, the diabetes was also associated with certain other issues that may amplify the identity of diabetic, most importantly the label of losing the sexual and reproductive health. The female respondents (in child bearing age) were having fear of being labeled as diabetic due to having general communal perception of producing infertility with sugar (diabetes). As mentioned above, a case study was found where a female respondent was labeled (and divorced later) as infertile due to her diagnosis of diabetes.

The general perception of losing sexual and reproductive health attacks the female social identity the most. Other fears were found to be attached with weakness and low output in work (both domestic and professional). Most of the respondents did not fear or felt challenged due to diabetes at large, till the aftermath that it has created in the already patients of diabetes such as losing of sight, losing of a leg (second most reported fear).

Since diabetes was not found to be immediately painful, thus related with certain end result of diabetes. Most of the respondents were associated with an additional identity of having sugar (also that may rest in eye or leg or in the reproductive organs). The respondents feared that they may lose some of the above mentioned due to diabetes, and may be considered socially handicapped.

## 7.2. Education

It was found that only a few of the respondents achieved high school/college degree. Most of the respondents were found to be not educated, whereas only 20% were found to achieve primary education. The education of the respondents were observed as a major indicator in not comprehending to the physician's prescribed treatment.

A few of the college graduate respondents were found to be adherent towards proposed treatment as compared to the respondents having low or no formal education. It was generally found that the non-adherence was directly proportional to/with the education of the respondents. Only a few cases (not educated female respondents) were found to be adherent (mostly due to their treatment supporter, a male member usually having basic formal education).

On the other hand, most of the not educated respondents were found to be inclined towards alternate and support treatments. However, home based remedies were used by both educated and uneducated respondents. The *Chak Mangla* water was interestingly used by both, educated and non-educated respondents.

The educational background of the respondents was however important in comprehending for/towards the lifestyle change counseling session(s). The male treatment supporter accompanying female respondents were found more active in understanding the counseling session as compared to the female respondents (herself). A female respondent shared it as:

*Mein tay parhi likhi nhi tay mein apnay banday kolon ilaaj sikhdi tay samjhdi aan. Mein tay apnay banday toun he sehat day paigham samjhay nain. Unhan nay he menoo ilaaj samjhaya aiy.*

Translation:

Since I am not educated, but I believe that my husband may have better understanding towards the proposed treatment. He is able to teach me the first



counseling session though I was fully involved in it. He was able to interpret most of the messages for me. (Adherent female)

A male educated respondent shared that the proposed treatment (including follow up checkups) is more logical to him. He further stated that he has learned to live with diabetes and keeps on sharing his issues over the follow up checkup with the physician, and lifestyle problems with the paramedic. He also expressed that:

*Mein waday doctoran noo vi check karwaya aiy tay naal parhay likhay yaaran, belian naal mashwara vi kita aiy. Shehar day ik doctor sahib nay akhri saal ik pamphlet tay kitabcha vi dita si.*

Translation:

I have not only consulted the waday doctor (doctor at DHQ and private physician in Sargodha city), but also peers (mostly educated) regarding diabetes. I also read some literature shared by my friends, and also by the private physician I visited last year in Sargodha city. (Adherent male)

Most of the respondents did find and rely on the opinion(s) from the educated community members. It was also found that most of the female respondents relied heavily on the opinion of male family members (especially educated family members). The level of education had a clear relationship with the level of adherence (i.e., number of follow up visits to the RHC).

### **7.3. Role of paramedic**

The paramedic was found to be the local resident of *Chak* 104 NB. It was also observed that the paramedic was very social during his duty hours and even afterwards. The general culture of village is interactive, and was thus reflected through the personality of the paramedic. The nature of interaction with the patients of diabetes was not only interesting, but demanding in a way where patients did rely on the suggestions, opinion and ideas shared by the paramedic.

It was found that most of the patients did ask questions in the first counseling sessions regarding the understanding of the messages (as delivered with the help of counseling tool on lifestyle change). The range of questions however changes in the follow up visits as explained by the paramedic as:

*Mera kam tay sugar day marizan noo sikhana tay dasna aiy. Pehlay session vich mareez ghat sawal jawab karday nay. Pehlay session vich bimari day mutaliq sawal jawab honday nay. Baqi sessions vich tariq e ilaaj tay naal khaan peen tay warzish day masail tay sawal jawab honday nain.*

Translation:

My job is to convince them regarding the management of their diabetes. The first counseling session with the respective patients were less interactive in terms of asking critical questions. Most of the questions asked in the first session (with different patients) were about learning the intensity of the diabetes and managing it with the delivered messages. The follow up visits brought certain queries, especially regarding the management of diet with local lifestyle and irregularities and issues in daily exercise.

The questions were explicitly asked by the male patients as compared to the female patients. Whereas, the elderly female did ask questions on their follow-up visits, especially regarding the issues with diet and exercise. Most of the female patients were accompanied with a family member (mostly a male family member) who used to ask questions on behalf of their female family member (patient). The paramedic was found to provide local solutions to the problems faced by different patients such as:

1. What is a healthy diet?
2. Why not to have sweet tea or any other sweet drink (especially in summers, and tea in the breakfasts and evenings)?
3. Decision of *Handi*?

4. Concept(s) of oily and fatty (*thinda*<sup>205</sup> *khana*)?
5. Daily activity confused as exercise?
6. Where to perform daily exercise (especially in case of female patients)?
7. Timings for the daily exercise (especially in case of male patients)?
8. Perception about local sweets and fruits?

The paramedic was found vigilantly important in answering the above mentioned pool of questions (with range of probes by different patients). The paramedic was found to be effective in convincing the patients with local examples. The paramedic also interacted more frequently with nearby working patients (male patients) and made them acquaintances. The paramedic was also found helpful in sending reminder calls for follow up visits (direct call to male patients and to treatment supporter of female patients). The paramedic not just reminded the patients regarding their upcoming follow up visit(s), but also made extra effort in reaching them (in case if the number was not responding).

The paramedic shared that he has used a friendly way to convince and respond to the patients, and the respondents also did share the same regarding the attitude and behavior of the designated paramedic. A male respondent shared that he works nearby the RHC and was able to remain regular for the scheduled follow up visits due to his acquaintance (made after his diagnosis) with the paramedic.

Most of the adherent patients relied heavily on the suggestions shared in response to certain questions regarding the curability and management of diabetes as expressed by a male adherent patient as:

*Chothay doctor sahib nay menoo desya kay fikar di koi gal nhi. Unhan nay mera mobile number vi rakh lya si takay menoo baar baar yaad karwa sakan. Unhan di waja toun mein apni sugar di rakh chak tay sambha karda haan.*

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205 Thinda is oily, food cooked in ghee or desi ghee in the context of the study

Translation:

The paramedic told me that I don't need to worry about the management of my diabetes. He also took my contact number and reminded me regarding the follow-up visits. He provided me examples that helped me to remain vigilant for any danger sign, and especially how to manage my daily routine with diabetes.

An elderly female respondent shared that the paramedic was very kind towards her condition of diabetes, and comforted her son (accompanying treatment supporter) on the first counseling session as:

*Aiy (Maa gee) Allah day hukan naal bilkul theek ho jaan gay. Tusan jivain jivain ilaaj tay ehtiat dasi aiy oo karo. Tusan inhan noo turan vi lay kay jao tay shoro ghar day sehan toun karo*

Translation:

She will be all fine with the grace of God. You must follow the given advice and also remain active towards her daily lifestyle. You may accompany her for daily walk, and you may start this even with a few steps in your courtyard.

According to most of the respondents, the paramedic delivered the counseling session in the local language (and also gave local examples) to help understand the concentration of the message(s). The respondents also shared their fears and challenges during the counseling sessions, and found paramedic as an important position towards finding the local channels of convincing towards the adherence of proposed treatment. The paramedic also gave reminder calls to the patients (and their treatment supporters) in a friendly manner. The adherent respondents shared that the paramedic not only reminded regarding the follow up visit(s), but also advised to visit at a time (in a given week) where the respective situations may be discussed in detail (during the follow-up sessions).

The paramedic on the other hand was also a prominent person in the community where patients (of different diseases) not only shared their respective problems (social, cultural

and financial issues related to the respective diseases), but also asked for the free opinion. The paramedic (even off duty) was taken into account due to in terms of his association with the RHC. The role of paramedic was found to be of importance towards finding channels of adherence (in local settings). The local wisdom of paramedic may also be considered as an important tool to provide solutions and suggestions to certain local fears and issues (emerging out of the diagnosis, label and management of diabetes).

#### **7.4. Perceived seriousness of diabetes**

Sugar, as a common term for diabetes not only reflects the perception of the disease (as discussed above), but perception towards seriousness of diabetes. Most of the respondents did find diabetes as something wrong with the ‘sweet’ within the body. It was interestingly found that most of the respondents did not find diabetes as immediately dangerous, and the sick role was temporary in most of the cases.

As also discussed above, the diabetes did not interfere greatly in the daily routine (of most of the patients). The respondents did not complain for any physical problem with diabetes as a core disease. The initial symptoms and diagnosis were also cross verified from multiple sources including the DHQ, traditional hakeem and private practitioners. The labeling of diabetes was also considered as that may be cured (in most of the cases). The respondents were not aware about the seriousness of the diabetes (till the counseling session). The counseling tool though did not mention any message (that may be terrifying to comprehend), but required the patients to understand the serious management of the disease. The general perception towards diabetes as a disease was found to be not fatal.

A female respondent shared that she did not find any major pain (in her body), and the restlessness was considered as the major cause of her weakness and pain in the legs. She further expressed it as:

*Menoo pata aiy kay menoo sugar aiy par mein theek ho javan gi (asi kafi ilaaj lahay nain).sugar da koi darn hi kyun kay jisam vich koi ziada takleef nhi. Hun*

*mein dopehri aram vi karni aan takay shami ghar walian wastay kam kaaj kita ja sakay. Sugar theek ho sakdi aiy wesay menoo roz roz masla vi nhi.*

Translation:

I know that I am diabetic, but I will get better with time and multiple treatment (that I am seeking since a month). I don't fear sugar as there is no major pain in my body. I have just started taking proper rest in the afternoon so I may work vigilantly in the evening for my family members. The diabetes can be cured and I don't see any challenge due to it in my daily routine. (Non-adherent female)

It was found that most of the respondents shared the seriousness of diabetes with intensity of pain (felt in the body) in legs and head. The respondents were found to administer the headache or any other pain with aspirin and also local methods such as taking warm milk and other home based remedies (instead of fighting diabetes at large). The perceived seriousness did greatly influence the proposed treatment and especially the proposed lifestyle change.

The seriousness was also found to have negative adherence relationship with the duration of disease. Most of the respondents generally took the first few steps of the episode of diabetes as comparatively serious. Longer a patient (regardless of gender) lives with the diabetes, was less likely to actively make an effort towards adherence. The local perception of the initial symptoms and seeking an advice (including peer, community members, dispenser, holy man, traditional medicine expert and biomedicine) were explained as more serious approach as compared to attitude changing with post label and acceptance of the label of diabetes.

The perception of the seriousness of diabetes were found to be an important factor towards the adherence of proposed treatment. More a patient considered it serious, better were found the outcomes through clinical adherence. The respondents were also found to take the clinical advice serious with number (and even frequency and size of pill). The management of diabetes through lifestyle modification only was not considered as

serious by any of the respondents. The perception of the seriousness of diabetes (as a disease) had range (changing with proposed drugs), and also comprehension towards the messages delivered through lifestyle counseling.

## **7.5. Environmental factors**

The changing environmental factors were found to be strangely connected with the adherence towards proposed treatment. Change in the household economy, mechanization of transport, geography, ecology, available health care options to the environmental situations at work, home and in public etc., may contribute both, positively and negatively towards the adherence.

The most important factor within the environmental factors was the weather condition of *Chak* 104 NB as shared by most of the respondents. The general climate (in most time span) is warm, and may get humid and even suffocating warm in summers. Most of the respondents did share how summers (as a season) is comparatively harder to manage or adhere towards proposed treatment. It was shared by adherent respondents that the days (dawn till dusk) are longer in summers with intense heat, and it force liquid intake, especially sweet drinks including (lassi, sharbat, and soft drinks etc.). The summer season also restrict daily physical activities including commute to work through mechanized transport (especially in case of male respondents), and there is a general feeling of weakness (both male and female).

A male adherent patient shared that he has started commuting to work (going towards his fields) by walking (instead of using motorcycle). He further shared that it is very hard to walk in summers especially in the morning and in afternoon. He expressed it as:

*Mein roz kam tay jaan wastay walk karna, mera office taqriban do kilometer door aiy. Garmian vich tur kay jana oo vi do kilometer bara okha kam aiy. Garmian vich turan phiran da masla honda aiy. Mein koshish karna kay tarkay ya rati chal phir lawan takay garmi di shidat toun bach sakan.*

Translation:

I try to walk twice in a day towards my work that is about nearly two kilometers away from my home. However, the summer season did not allow me to walk (especially when it was best suited for me to walk daily). The summer season greatly influence my daily routine in terms of physical activity. I try to walk in the night or early morning to avoid heat of the summers, but it is hard to daily maintain this routine.

The climate along with work environment also added towards adherence. The profession of different male respondents did influence the daily lifestyle including working hours, daily commute, available options to eat (especially in lunch time) and work stress at large. A male respondent expressed the work stress as:

*Daftar vich ajeeb siyasat aiy pichlay saal toun, menoo khatra aiy kay paki nokri na chali jaiy. Menoo aaj kal koi vi shay yaad nhi rehndi, dawai tay parhez tay door di gal aiy. Menoo yaad aiy kay mein unhan dinan vich tambakoo noshi vi kiti aiy tay mood badlan wastay meetha vi ziada khada aiy.*

Translation:

The politics within the organization was ugly since last year and I had fear of losing my permanent job. I lost my concentration towards everything, especially taking medicine at prescribed time and following a healthy diet. I still remember that I not only smoked during the stressed days, but also took sugar to fight with my low feelings (non-adherent male)

The female respondents shared that the geography of the village does not allow space to adhere towards the prescribed daily exercise. Most of the female respondents shared that the living space and rooftop also have limitations for daily exercise. The space in general is overwhelmingly crowded by the male members of the village. Only a few female respondents had the access to the dera and their fields for daily exercise (in early morning).



The holy month of Ramadan did change the lifestyle as shared by most of the respondents. The respondents shared that it does not only influence the practice of fasting but the general routine including timings of the meal (what to eat early morning to fast) and (what to have to break the fast). The male respondents also shared that there is less time for daily exercise especially in the month of Ramadan as more time is spent in praying and performing itikaf<sup>206</sup> (*'tikāf, also i'tikaaf or e'tikaaf is an Islamic practice consisting of a period of staying in a mosque for a certain number of days (last ten days of Ramadan), devoting oneself to ibadah<sup>207</sup> during these days and staying away from worldly affairs*).

The long distance work places influenced the male respondents in a way that they now use mechanized transportation. Most of the professions are also mechanized and more sedentary. The food (mostly in the lunch time) are cooked in oil and with more salt (to attract the local taste). A male respondent shared that the trend is changing, where nearly all of the male members of the village used to bring home made lunch on their respective places. Another male respondent shared that the food industry has generally changed in the last few years. He further stated that the food and lifestyle does not match anymore. He also expressed that the refrigeration of food has changed the entire practice of cooking at least in his home.

## **7.6. Health illiteracy**

As mentioned above, the situation of the education of the respondents was found to be an important factor towards adherence to the overall proposed treatment. The general health literacy was found poor amongst female respondents (especially elderly female patients). The male respondents were found to be better towards basic numeracy skills (to manage the drugs) and general knowledge (to comprehend lifestyle counseling).

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<sup>206</sup> *I'tikaf* is a practice of staying in the mosque and performing extra deeds of devotions in the absence of public scrutiny (Rasdi, 2014).

<sup>207</sup> Ibadah are prayers

Most of the female respondents relied heavily on the literacy level of their treatment supporters as expressed by an elderly female respondent:

*Mein likh parh nhi sakdi tay mera putar meray wastay nuskha tay dawai parhda aiy. Unhain meray wastay ik kitaab banai aiy jidhay vich oo dawai tay parhez da hisaab kitaab rakhda aiy. Jay unhon koi kam pay jaway tay meri wadi poti noo samjha kay janda aiy. Meri poti hun satveen vich parhdi aiy.*

Translation:

I cannot read or write, and I am dependent on my son to identify the right drug and also the frequency and time of the drug. He has made a chart for my drug(s) and also for my diet. In case if he is away, he teaches my granddaughter (eldest amongst her siblings) to identify and remind me about the drug(s). She is a student in the secondary level school. (Adherent female)

Another female respondent shared that her daughter in law has made a chart for the drug(s) though she herself is uneducated like the respondent, but takes help from her children (as all of them attend school). She further explained that initially she had over and less dose at times. She also smilingly expressed that her grandchildren keep an eye on her healthy diet as per the direction of their father (son of the female respondent).

Most of the respondents did understand the pictures in the counseling tool, (but confused the messages related to it later). The paramedic (as observed) was vigilant in delivering the required messages in the local language and dialect. Most of the respondents were also found to rely on the information (as heard from a different family and community members). The wall chalking and advertisements by the alternate treatment claimers were read and interpreted by less number of people (who then interpreted the advertised claim for certain diseases).

The communication was found to be a complex process as most of the respondents were less or uneducated. The understanding of certain clinical terms and health education messages were interpreted with the lens of local wisdom, such as warm or cold, weak and

strong, low and high, curable or deadly etc. The communication between the respondents and physician was found to be limited and formal as compared to the paramedic, whose pattern of communication was relaxed and less clinical.

The communication with the alternate and support treatment providers was generally better as it was mostly in the local terms, and they were also able to offer the interpretation keeping in view the fears and psychology behind the local understanding of diabetes as expressed by a non-adherent male respondent:

*Hakeem sahib noo meri tabiat day mutabiq gal samjh vich ai. Menoo pata aiy kay sugar theek ho sakdi aiy tay zaruri nhi kay sari zindagi sugar da ilaaj karwaiay. Unhan noo meray jism vich kithay kithay takleef kis tarah di hai samjh lag gai. Mein apni gal baat waday tay chothay doctoran noon hi samjha paya tay unhan noo vi samjh nhi ai.*

Translation:

The Hakeem did understand my point of view. I knew that the diabetes is curable and I may not keep on living with it. He did understand that how I feel inside my body (while touching his head, shoulders and arms). I wasn't able to communicate my fears and understanding with the physicians and paramedics, and they were also unable to understand my feelings with diabetes.

A female respondent also shared that the holy man cannot only heal the diabetes but also other social problems related with it (her recent divorce, infertility etc.). She also stated that formal education has nothing to do with the understanding of medicine. The treatment prescribed by the holy man was not just simple to comprehend, but also easy to manage as shared by the respondent. She further stressed that the holy man also understood the cause of her diabetes, and was able to comfort her with detailed spiritual counseling session.

The health literacy was thus found to be a complex process of communication (between patient and health care providers), dire need of understanding the local interpretation and

key terms associated with diabetes, use of treatment supporter in the required numeracy (for the management of drugs) and understanding the local social capital that goes beyond the narrow clinical concept of health education and its literacy.

## **7.7. Age**

The age of the respondents were found to be an important factor towards adherence. Most of the respondents were found to be aging quickly especially due to certain socio-cultural factors including:

1. Less physical mobility
2. Poor financial status
3. Dependency on children and grandchildren
4. Less or no education
5. Stress

The age of the respondents also demands residential nursing care especially for their diet, scheduling of drugs, space and time for exercise, cleanliness, and above all, a healthy environment. The gender in aging also played an important role as the female respondents were more dependent on their family members. Male respondents (in case as head of the house) were found to be more active in seeking health care (visiting health facility and other available treatments).

Most of the female respondents were in the age bracket where their social and domestic roles have changed, and also the level of dependency (especially in case of a widow living with her son and his family). The female respondents shared that with age, though physical problems have strengthened, but the social and domestic respect is in a better position (especially in case of elderly females living with their son).

Both male and female respondents shared that the fast pace of urbanization and processes of modernization creates a distinct situation of discrimination especially in case of understanding and comprehension of health education, awareness, and management of

certain health issues. A female respondent sadly shared that the hospital itself is so clinical and the information is often advertised through banners, mounted pictures in wooden frames and wall drops. The awareness messages are also spread through pamphlets and other means (counseling tools). Most of the messages are advertised in English and Urdu languages. The processes and long queues also affect the physical situation of the patients. A male respondent shared that information (on all over the walls of RHC) are useless of old uneducated patients (for that they rely on others to read and interpret).

Most of the respondents did share that aging seriously affects the mobility (that directly affects the proposed daily exercise), diet (as unable to change dietary habits) and understanding of the disease (considering diabetes as curable and seeking multiple treatments that are easy to comprehend and manage) and culturally endorsed methods (to cure, manage and treat diabetes). The age also reflected strong psychological dispositions towards the identity as a diabetic, retired life, changing social and domestic roles, and dependency for transportation and traditional methods to commute and understanding the information.

An elderly non-adherent female respondent shared her feelings as:

*Mein budhi aan tay har welay di kamzoori vi aiy. Mein tay apni noo di muhtaj aan. Menoo mera putar hospital wegheera lay kay janda aiy. Mein apnay ap nhi ja sakdi na jani aan. Putar farigh hovay tay lay janda aiy.*

Translation:

I am old and remain tired all the time. I am so dependent on my daughter in law to provide me daily meals. I am also dependent on my son to take me to the health facility in case of emergency. I am unable to go on any follow-up visit (even after certain reminders from the paramedic) due to the bust schedule of my son (in his business activities).

A non-adherent male respondent presented his dilemma of aging and diabetes as:

*Mein das saal pehlan billul theek thaak si. Rozay namaz vi sit ay kam kaaj vi par hun har welay madad chahi di aiy. Budha banda umar day naal nhi balkay ikhtiar day naal honda aiy.*

Translation:

I was so active only ten years back. I used to fast and used to work daily, but now I am always in need of a support (especially in case of health emergency). The old is not by age, but by lack of authority and say in the decisions.

The age of the respondents were found to be very active towards both adherence and non-adherence. The elderly respondents were generally dependent on the family members (especially a male family member) to transport, accompany and also become treatment supporter (especially understanding the proposed treatment and manage it with the patient in the home).

## **7.8. Summary**

It was found that certain socio-cultural factors may influence the stages within the episode of diabetes. The decision making process (towards diagnosis and treatment) was also found to be greatly influenced by certain factors that may overall affect the perceptions and practices towards care seeking (of/for diabetes). The patients' perspective (through the patients' explanatory model) was found to add in the existing knowledge as beyond clinical understanding towards diabetes care package. Certain decisions (towards diagnosis, treatment, follow-up, lifestyle modification) were found to be strongly constructed by socio-cultural factors including the domestic and gender hierarchy, opportunity cost (for seeking treatment and remaining regular towards proposed treatment), cultural perception(s) towards food (especially sweet), physical activity (especially exercise) and perception towards curability of diabetes (instead of management).

The adherence to the proposed treatment (in specific) was found to be affected by both, direct and in-direct factors. The treatment was found to be two pronged (i.e., clinical treatment and lifestyle modification). It was found that the clinical treatment (diagnosis, prescription and drugs, follow-up visits) was majorly affected and influenced by various social factors (both direct and in-direct) as explained in the flow chart below. The direct social factors towards adherence to the clinical treatment were the perception(s) towards public health care system, role of paramedic, opportunity cost and social identity of diabetic. The in-direct factors were also found to be cross cutting with the direct social factors. The in-direct factors were the overall environmental factors, education, health illiteracy and age.

The adherence to the lifestyle modification was found to be mostly affected by certain cultural factors (both directly and in-directly). The direct cultural factors that may affect adherence to the lifestyle change were the concept of diet, concept of physical activity, gender and perception towards the treatment of diabetes (especially desire for cure and maximum benefits). The in-direct cultural factors were also found to be cross cutting with direct cultural factors that may include perceived seriousness of diabetes, financial pressures, position status in the family and environmental factors. A flow chart regarding the cultural factors affecting the adherence to the proposed treatment is designed below.

It was found harder for female patients to adhere the follow-up visits (as scheduled) in general. The female patients were found to be more desired towards seeking cure (for diabetes) and maximum benefits (in case of opting for treatment). The male patients were found to celebrate more liberty and freedom through their position/status in the family. The domestic hierarchy was found to adversely affect the female patients (especially in case of a wife, living with in-laws). The diet and exercise was difficult to adhere for/by female patients as compared to the male patients. The overall adherence to the proposed treatment was majorly influenced by the gender (of the patient). The cognition was greatly influenced by cultural factors mostly, including the traditional preference for oily and salty foods, sugary items, meal planning and role of religion (and rituals). The perception(s) towards physical activity was found to be confusing (and was considered as

an urban phenomenon) by different respondents. The exercise was found to be compromised with/by the issues of time and required space. The female patients complained about the appropriate space (required) for the suggested daily physical activity. The cultural and traditional permission was found to be a prerequisite for modifying the existing lifestyle (especially in case of female patients).

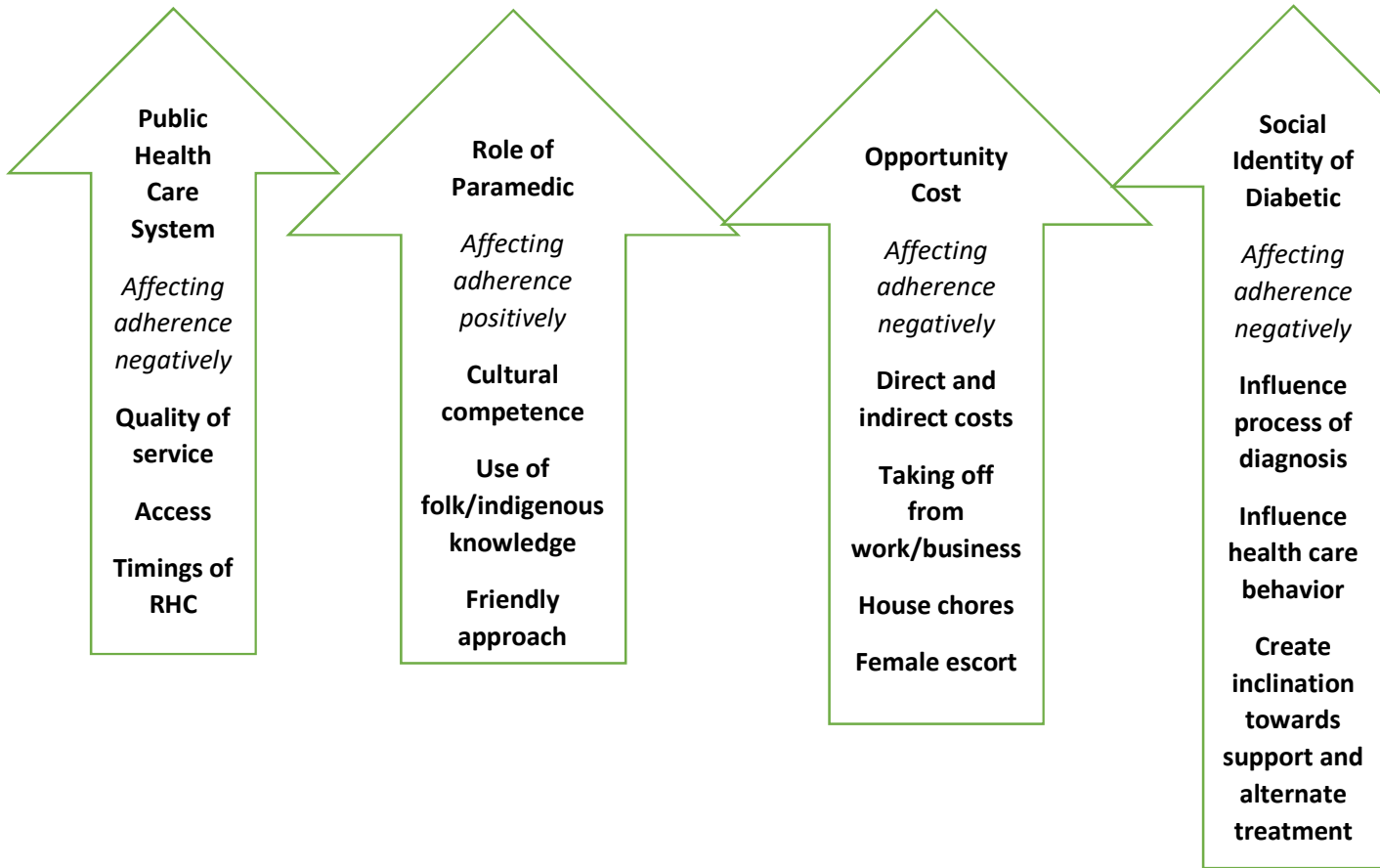
The clinical treatment and lifestyle modification was found to be affected by certain (specific) socio-cultural factors (as summarized above). However, few cross cutting factors were also found that affect the overall treatment (decision making process and management of diabetes). The general factors included the background of respondents in terms of their formal education, health illiteracy, perceived seriousness of diabetes, social construction of the new identity as diabetic, age, environmental factors and the role of paramedic.

The patients' explanatory model did provide insight of/to the different stages/journey of diabetes, including the cultural perception of cause of diabetes, perception towards time and mode of onset, pathophysiological explanations, expression towards severity, the decision making process/care seeking process towards treatment, and factors that may affect the adherence towards the proposed treatment (clinical treatment and lifestyle modification).

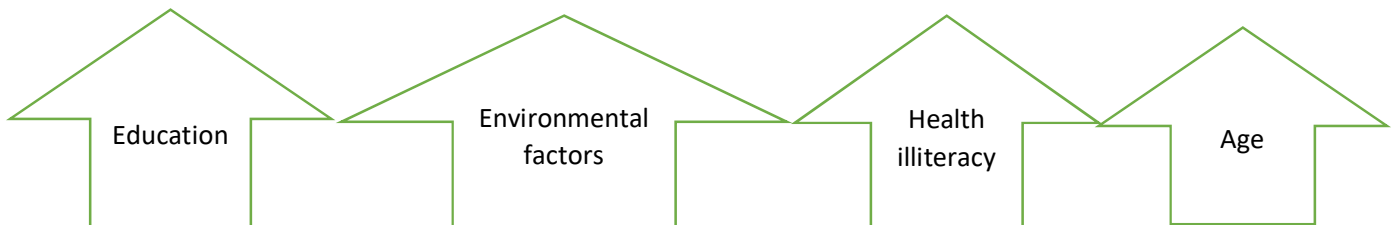


**Social factors influencing adherence to the treatment**

**DIRECT FACTORS**

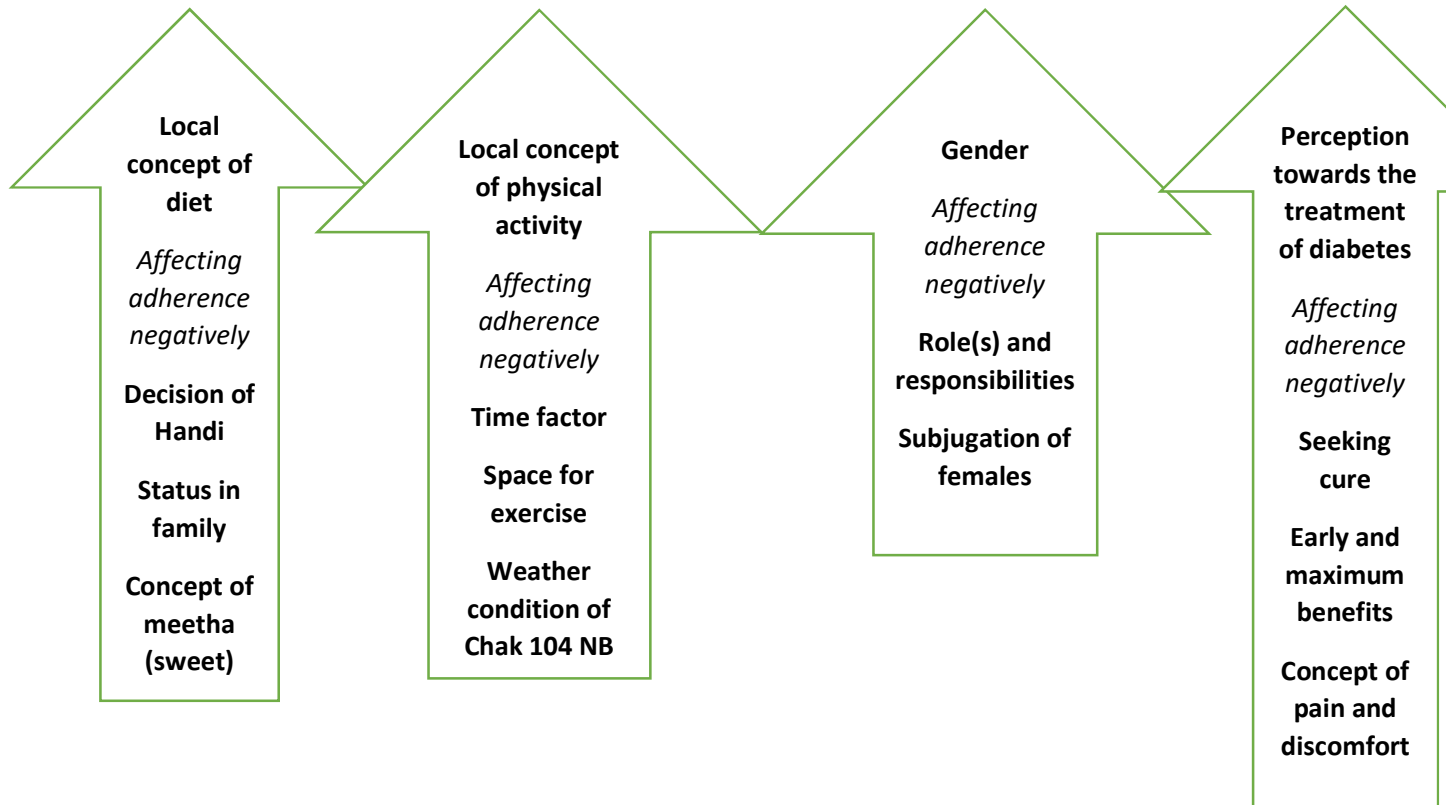


**INDIRECT FACTORS**

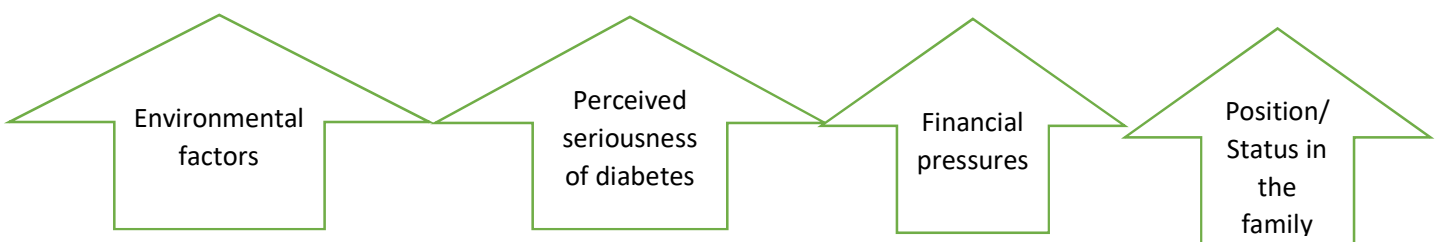


**Cultural factors influencing adherence to the treatment**

**DIRECT FACTORS**



**INDIRECT FACTORS**



## 8. DISCUSSION

The study found a strong correlation of both social and cultural factors that may affect and influence (both negatively and positively) the adherence to the proposed treatment (implemented through pilot intervention in the selected health facilities of district Sargodha). The explored episode of diabetes with the help of patients' explanatory model suggest beyond clinical understanding as an important aspect for the scale up of the intervention in the province of Punjab.

'Sugar' as commonly known term for diabetes was also found to be richly loaded with cultural perceptions and social factors stretched along its stages of episode, from perceived etiology to seeking treatment(s), it is found to be a complex socio-cultural construct that may help understand the position and grass root problems at patients' end. The adherence to the proposed treatment (both clinical treatment and required lifestyle change) was also a product of various direct and in-direct social and cultural factors. The study was able to find various important themes in the due course of different stages of the said episode. There are certain specific factors (as discussed in detail in the previous chapter) that affect the adherence negatively and may also delay the compliance (i.e., regular follow up visits and adherence to the diet and exercise). The specific factors that affect clinical treatment holds much larger social picture as compared to the specific factors affecting adherence to the lifestyle modification. The lifestyle change was found to be more cultural and cognitive in terms of its decision, process and practice as compared to the clinical treatment which is more macro and was found to be influenced by multiple factors.

The perception of the respondents were found to be of great importance and relevance towards the proposed treatment, and it has helped to construct a much larger picture that includes the perception of target population for better outcomes. Another study (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, Explanatory models of diabetes: patient-practitioner variation., 1994) also emphasized on documenting and understanding the patients' perspective with the lens of explanatory model that may help to contribute designing a better framework of improving compliance/adherence. Similarly (Tripp-

Reimer, Choi, Kelley, & Enslein, 2001) discussed that larger cultural context is very effective in the understanding, designing and implementation of diabetes care. It is also emphasized by the same study that socio-cultural factors are of great importance to understand, as they affect all aspects of diabetes including the perception, process of diagnosis and treatment at large. A study (Osman & Curzio, 2012) also stressed to explore the cultural determinants that may help design holistic care in case of chronic diseases and diabetes in particular.

As discussed above, that the current study has explored and documented the complex nature of diabetes as seen and explored through the lens of respondents, and may be found consistent with earlier studies that also label and explore diabetes as a multi-factorial disorder (Szathmary, 1994) (Hales & Barker, The thrifty phenotype hypothesis, 2001) (Hales & Barker, Type 2 (non insulin dependent) diabetes mellitus: the thrifty phenotype, 1993)

The study also found a different perspective as compared to the clinical nature and understanding of diabetes care. The current study had insights as a lived experience of diabetes that may be useful in further capacity building and content design (for health education tools) of primary public health care system. The local perspective was not only insightful, but the subjective realities also produced certain common themes that may be considered as serious approach in understanding the adherence towards the treatment. The subjective perspectives are also backed by other similar studies who have used Anthropological perspective towards explaining the diabetes as lived experience, which is the need of the hour and may reflect a sensible subjective lived experience of diabetics. (Mendenhall, Seligman, Fernandez, & Jacobs, 2010) (Rock, 2003) (Young, 1980).

## **8.1 Social factors**

The study has found various social factors that may be considered as important gates to understand the adherence towards the clinical treatment, including the diagnosis, prescription and drugs, and follow-up. The factors that may directly affect the above mentioned clinical treatment are the perception towards public health care system, role of

paramedic, financial constraints in achieving compliance towards proposed clinical treatment, and the social identity of diabetic.

The perception towards the public health care facility was a major finding that has influenced patients to cross validate the diagnosis and label. The quality of public health care system was not well celebrated among the respondents (diabetics) in particular, and patients (who visit RHC) in general. The trust automatically shifts towards private practitioners that may give/provide comparatively more time and may also understand the psychological needs of the recently diagnosed and labelled patients of diabetes. The trust on the private practitioner is strengthened due to the timings and availability of physician in the evening (as compared to the strictly morning timings of public health facility). The hierarchy within public health system such as district headquarter, tehsil headquarter, rural health center and basic health unit is considered as quality graph with the best at the top and poorest at the basic units. The respondents also rely heavily on the opinions of private practitioners (especially who does clinic in the city). The term '*wada* doctor' holds significant and visible position in the process of verifying the diagnosis (done at the RHC). The unavailability of time (at the physicians' end) at the RHC was also observed as a factor that pushes patients outwards and pulled inwards by the other methods of treatment (as discussed in the previous chapter).

The public health care system does complete various tasks related to each and every patient in a short span of time and leaves unsatisfactory feelings. It is also consistent with various other studies that reflect similar emotional, psychosocial and behavioral issues as problematic factors in a short time bracket (Eytan & Goldberg, 2001). Issues related to accessibility and availability is another dimension that may be found consistent with the current study (Ponnusankar, Surulivelarajan, Anandamoorthy, & Suresh, 2004). The wait time at health facility was also a similar issue that was found in other studies (Grunebaum, et al., 1996) (Balkrishnan, et al., 2003) (Moore, et al., 2004) (Lawson, Lyne, Harvey, & Bundy, 2005) (Wai, et al., 2005). The compromised satisfaction after health facility visit may contribute towards poor adherence and was explored on similar lines by other researches (Spikmans, et al., 2003) (Gascon, Sanchez-Ortuno, Llor,

Skidmore, & Saturno, 2004). Another study explained by (Haynes, et al., 1980) explains that patients' satisfaction may improve compliance, and is consistent with the findings of the current study.

The current study, however, found that the active role of paramedic may improve the adherence. The personal dedication towards patients' follow-up communication was useful in the compliance to the scheduled visits. The paramedic did interpret the counseling tool with local examples, and also provided contextual based solutions to the issues raised such as exercise for females, interpretation of healthy diet, and support and home based remedies. The paramedic was also found discussing critical issues of patients' using support treatment, such as *Chak Mangla* water and seeking alternate health care. The paramedic did provide balanced approach to understand the position and barriers towards coping with the recent label of diabetes and managing proposed lifestyle. The role of paramedic did influence the overall adherence by making a friendly contact during the counseling session(s) with the diagnosed and registered patients. The follow-up reminders were also conducted by the paramedic where he convinced the registered patients to appear/attend scheduled follow-up visit regardless of their gender. The respondents also did rely on the indigenous solutions provided by the paramedic during the follow-up visits. The service provision in terms of paramedic was found influential in the adherence towards the proposed treatment, but the complaints remained the same towards the general quality of the public health care system. It may be registered that better patient-provider communication may influence the adherence positively (at least towards follow-up visits). Several articles evaluated the effect of the patient-prescriber relationship to patient's compliance. It was inferred that patient-prescriber relationship is a strong factor that affect patients' adherence and is also emphasized by (Buck, Jacoby, Baker, & Chadwick, 1997) (Roter & Hall, 1998) (Stromberg, Brostrom, Dahlstrom, & Fridlund, 1999) (Kiortsis, Giral, Bruckert, & Turpin, 2000) (Okuno, Yanagi, & Tomura, 2001) (Kim, et al., 2002) (Loffler, Killian, Toumi, & Angermeyer, 2003) (Moore et al 2004) (Gonzalez, Williams, Noel, & Lee, 2005), their findings are similar to the current study.

Couple of studies are also found consistent with the current finding(s) of supporting patients emotionally, and dealing with their issues in their language and context (Moore, et al., 2004) (Lawson, Lyne, Harvey, & Bundy, 2005). The role of health care provider was also researched on similar lines, and have concluded that poor communication or lack of concern in patients' problems may lead to poor adherence towards the proposed treatment (Bartlett, et al., 1984) (Apter, Reisine, Affleck, Barrows, & ZuWallack, 1998). Lim and Ngah also showed in their study that non-compliant hypertension patients felt the doctors were lacking concern for their problems (Lim & Ngah, 1991). In addition, multiple physicians, or healthcare providers, prescribing medications might decrease patients' confidence in the prescribed treatment, as discussed by (Vlasnik, Aliotta, & DeLor, 2005) whereas, the paramedic in the current study did manage to answer the issues raised by the patients and also provided contextual recommendations towards achieving adherence towards clinical treatment and lifestyle change.

The adherence was also influenced by the economics of diabetes. The respondents were found to calculate the follow up visits in terms of creating cost vis a vis curability. Each visit was planned keeping in view the distance, morning timings of the RHC, availability of the doctor and paramedic, taking a day off from work (especially in case of escorting the female patient), difference of agrarian and industrial calendars and working hours, mode of transport, and daily house chores (especially in case of female patient).

The cost was also calculated in terms of number of visits and getting cured, instead of learning the management of diabetes (especially through lifestyle change). The working hours were compromised on the day of follow-up visit along with the arrangement of transport to reach RHC. The patients preferred visiting early (even before the opening of RHC) to avoid long queues and tiring wait. The transport were arranged differently, keeping in view the gender of the patient (motorcycle usually for male and motor rickshaw for female patient) as female patients were mostly accompanied by more than one family member. The cost is arranged before the visit to pay for transport or return in kind (in case the transportation is borrowed from the nearby community member).

Taking a day off for daily wagers was also found to be a major hindrance towards compliance. Family members' plan it together to overcome the above mentioned, and is found consistent with a study conducted in India where patients and families usually meet the 95% cost of the treatment together as a unit, found by (Grover, Avasthi, Bhansali, Chakrabarti, & Kulhara, 2005). The unavailability of any platform, insurance or social protection, may lead to force out of pocket expenses in case of fighting the chronic diseases, and is also found relevant to the findings of a study conducted in the context of South Asian cultures, where the expenses are out of pocket due to lack of any health insurance schemes that burdens the household budget and compromises adherence, as discussed by (Nishtar, 2002).

The contrasting working hours may lead to force the patients to take a day off and also shorten visit to their farm business activities. Females, on the other hand, work extra or the elder daughter may take a day off from her school to complete the house chores. The above mentioned compromises adherence, and is also reflected by a few other studies (Shaw, Anderson, Maloney, Jay, & Fagan, 1995) (Siegal & Greenstein, 1999) (Hernandez-Ronquillo, Tellez-Zenteno, Garduno-Espinosa, & Gonzalez-Acevez, 2003) (Neal, Hussain-Gambles, Allgar, Lawlor, & Dempsey, 2005). An interesting finding regarding the white collar patients was also discussed that they may have other priorities that eventually compromise adherence to the treatment. The timing of health facility was found to create a major opportunity cost, as also found by an observational study in Malaysia, where housewives with tuberculosis were more compliant because they were able to adapt to the timings of the health facility as discussed by (Chuah, 1991).

The fear of not getting cured with each planned follow-up visit produces a non-compliant attitude. The lifelong management and treatment brings both direct and in-direct costs calculations. Cost and length of treatment would go hand in hand (especially in case of low income community), and is consistent with other studies (Degoulet, et al., 1983) (Cockburn, Gibberd, Reid, & Sanson-Fisher, 1987) (Shea, Misra, Ehrlich, Field, & Francis, 1992) (Frazier, Davis-Ali, & Dahl, 1994) (Apter, Reisine, Affleck, Barrows, & ZuWallack, Adherence with twice-daily dosing of inhaled steroids. Socioeconomic and



health-belief differences., 1998) (Berghofer, Schmidl, Rudas, Steiner, & Schmitz, 2002) (Benner, et al., 2002) (Ghods & Nasrollahzadeh, 2003) (Hernandez-Ronquillo, Tellez-Zenteno, Garduno-Espinosa, & Gonzalez-Acevez, 2003) (Mishra, Hansen, Sabroe, & Kafle, 2005) (Connelly, 1984) (Shaw, Anderson, Maloney, Jay, & Fagan, 1995) (Ellis, et al., 2004) (Ponnusankar, Surulivelarajan, Anandamoorthy, & Suresh, 2004) (Swett & Noonan, 1989) (Kaplan, Bhalodkar, Brown, White, & Brown, 2004) (Choi-Kwon, Kwon, & Kim, 2005).

The diabetes constructs a new social identity comprised of label(s) and stigmatization. The process of diagnosis involves a series and layers of opinions, starting from discussing the seriousness of the issue with the family members and moving towards more formal opinions (i.e., Imam Mosque, Hakeem, extended family members, dispenser and already diagnosed patients of diabetes in the community). The process of diagnosis defines the identity (of a potential diabetic), and is found to be social in its nature.

The registration at the RHC as a patient of diabetes was also discussed at different social gatherings (related to different patients). The discussion involves the seriousness of the diabetes, future planning of treatment, and seeking ways to find a cure. The gender of the patient also influences the social identity as a diabetic, however both male and female patients tend to negate the label of diabetic initially. The patients were visited by a number of family and community members and may be considered as a practice of validating the label of diabetes, the process of seeking health care and inquiring visits by the family and community members reconstructs a new identity. This labelling of new identity by the community brings part and parcel of multiple treatment opinions, hence compromises and delays the adherence to the proposed treatment. The construction and reconstruction of the identity through relationship and interaction of patients' with others is consistent with a study on chronic illness and biographical disruption by (Williams, 2000). Study conducted by (Amorim, Ramos, Brito, & Gazzinelli, 2014) also reflects on similar issues, as mentioned above, where type 2 diabetes patients were studied using the theoretical framework of representations of identity as a dynamic phenomenon comprised of representations of oneself as well as group representations. Another study also

reflected on the social relations helping to construct the identity of sick individuals (Deschamps & Moliner, 2009).

The stigma of infertility was found to be a major barrier for female patients in child bearing age towards adherence, and also seeking health care in general. There is less evidence available of stigmatizing infertility with female diabetics (in child bearing age). Whereas, diabetics often experienced a pressure from their families to conceal their condition for the purposes of improving their marriage prospects as discussed by (Singh, Cinnirella, & Bradley, 2012).

## **8.2. Cultural factors**

The lifestyle modification (in particular) was greatly influenced by certain cultural factors. Most of the factors were cognitively engraved in the perception of the patients, and was interpreted and practiced culturally instead of learning the clinical understanding and importance of changing the lifestyle as per the counseling session(s).

Most importantly the concept of diet and healthy diet was found to be a complicated cultural product that may also include components of/from religion and traditional wisdom. The decision of what needs to be cooked daily and distribution of portion was found to be influenced by patient's position/status in the family. The exercise was also found to be greatly influenced by the cultural understanding and interpretation of physical activity in the local context and grass root realities. Patients' perceptions towards treatment (in general) and perception of curability (in particular) shaped desires that helped explore and try other treatment packages that may cure (or give maximum benefits in a short span of time). The gender did also affect the adherence towards treatment in general, and required lifestyle change in particular.

Certain cultural factors affect adherence to the treatment directly that mostly include perceptions, especially towards seriousness of diabetes and treatment. The lifestyle modification was also compromised, especially due to the cultural conceptualization of diet, meal portions, combination, and most importantly the decision of *handi* at

household level. Barriers to physical activity were also overwhelmingly cultural (especially in case of female patients). The underlying beliefs and feelings were found strongly related to behavior, especially interpreted differently by different genders and hierarchical position/status in the family.

Diet was found to be the most complex dimension within the lifestyle change. The complex nature of diet that included culture, religion and tradition wisdom did compromise and delayed adherence to the proposed healthy diet. Within diet, *meetha* (sweet) were found to be interestingly significant. It may be considered consistent with an earlier study by (Sachdeva, Khalique, Ansari, Mishra, & Sharma, 2015) who have found the influential role of religion, religious gatherings and rituals, culture and economics in shaping daily diets (especially in South Asian cultures). The same study also shed light on the use of oil and sugar as an integral part of the daily diet in Indian families. The significance of sweets in religious festivals was found similar to the current study findings. In another study by (Bradby, 2002), conceptualization, preparation and consumption of food was found on similar lines with the current study, as mediated by both traditional and modern patterns and lifestyle(s).

The position and status in the family also influences the decision of *handi* in terms of what needs to be cooked. It was found to be a major hindrance in achieving healthy diet for female patients (in general). Other studies have also found the lack of family and dietary support towards women's health in general, and specific to advised diet, as discussed by (Adams, 2003) (Anderson, Freedland, Clouse, & Lustman, 2008) (Mercado & Vargas, 1989) (Savoca & Miller, 2001). The working hours and work related issues of diet were also found consistent with previous studies (in case of male patients), especially in the context of non-adherence to proposed diet as discussed by (Lopez-Azpiazu, Martinez-Gonzalez, Kearney, Gibney, & Martinez, 1999) (Kearney & McElhone, 1999).

The *handi* (in specific) was found to be gendered and was greatly influenced by the male gender (head of the house). The *handi* was male gender bias and the economics was also an influential part in deciding what may be cooked. It may be found similar to existing literature on the gendered nature of food preparation and cooking. A study by (Wood,

1995) explained how women have to consider the taste and other related requirements (of the family members) as top priority. Studies conducted by (Brown & Daisey , Gender role preference and family food chores, 2002) (Brown & Daisey, Couples' gender role preferences and management of family food preferences, 2002) also admitted similar accounts for low income women, where father's preference holds the strongest influence on family eating patterns. Same authors also found resources, convenience, needs and desires of the family members as important dimensions in the said decision.

The diet was found constructed as a cultural tradition towards its conceptualization and utility of/as healthy. The definitions, underlying beliefs and perceptions towards diet were found to be of great importance for patients. The religious importance of certain sweet dishes is one phenomenon, and confusing sweet fruits as only fruit is an additional phenomenon towards culturally healthy diet. The confusion was thus found in patients' perception towards what is healthy and unhealthy, or the quantity of fruits intake, sweet milk and tea, taking soft drinks, and having sweet dishes for religious purposes. It is consistent with a study that reflected confusion as a major barrier towards suggested dietary adherence as discussed by Vijan (Vijan S. , et al., 2005).

The second important component of the lifestyle change is exercise that, however, was also to be greatly influenced by certain cultural factors, including issues related to/with time, personal preference of the patient towards physical activity, and weather conditions. Leisure time and physical activity was found to be different from western construct of exercise, physical activity, and leisure in general. However, female patients from same ethnic background (especially sect) were found to create an informal network as a group, to perform walk in the early mornings or early evenings (keeping in view the weather conditions).

Apart from creation of an informal group of female patients (suffering from different non-communicable diseases), other factors were found to be similar with existing literature, including barriers of lack of time as explained by (Ford & Herman, 1995), and weather conditions shared by (Wanko NS1, et al., 2004). It may also be confirmed by other similar studies who have suggested certain factors including lack of time, weather,

and perceived illness and laziness irrespective of ethnic group that produces non-adherence, found by (Booth, Bauman, Owen, & Gore, 1997) (Eyler, et al., 1998) (O'Brien, 2000) and (Grossman & Stewart, 2003).

The concept of physical activity was mostly associated with house chores (in case of female), or doing work (in case of male). However, young male of the locale (*Chak 104 Shumali*) were found engaged in sports in the evenings. Females, on the other hand, were found mostly staying in the houses and socializing in a limited manner. Whereas, males were found to socialize more and may spend leisure time with other community members (from different ethnic backgrounds). The lack of socialization of women (as compared to men) for outdoor activities may be seen as a potential barrier to explore further prior to the design and implementation of lifestyle (exercise in specific) education. It is also consistent with an earlier study specific to female's physical activity and socialization, as discussed by (Eyler, et al., 2002).

The concept of time (for physical activity in specific) was found to be an emerging concept in the study locale. The concept of physical activity (specific to proposed brisk walk) was also found to be a new style that may be interpreted subjectively. The old community members (male) were observed walking in the late evenings (for the purpose of going back to their respective places after a social gathering). The walk observed was not brisk (as done usually), and may be considered as an obstacle in achieving the required targets from the proposed physical activity. Females (especially old patients) did greatly confuse the house chores as a major physical activity, apart from a few patients who had space (*dera*) to perform walk (especially early morning).

The gender was found to heavily influence the understanding, interpretation, and practice of the entire episode of diabetes. The subjectivity of interpreting the stages of the episode leads to different meanings, and also subjugation (in case of females) in adherence towards treatment (for female gender). The concept of good and resourceful woman (in rural Punjab) is considered to be the one who never gets sick (may never take a day off from her domestic responsibilities). The list of responsibilities ranges from producing off-

springs, to nurturing the children to complete daily house chores (washing, cleaning and cooking in most cases).

The priority for women was found to be her house (and family members). However, the role and responsibilities change with growing age of females. The age also changes the status and nature of political hierarchy within the house. The change in status still leaves the women to be complemented in her decision making (by her son as a replacement to her husband). Not just the domestic spaces, but the space overall was found gendered that created a strong influence in adhering to exercise and diet. The process of diagnosis and finalizing treatment was also co-decided (in all female cases) by the male member(s) of the family. Women also take into account the lines drawn by the male members as a norm (especially in case of seeking health care). Women exhausted channels that are culturally endorsed and acceptable, as compared to reaching RHC as their first/priority option.

The female patients were found to address the sick health at household level for a longer span, as compared to male members (as he must not take a day off from work/business, thus leading to a quicker health care decisions). The concept of health and health needs was found to be more male-centric, the lifestyle of male were found to be accommodated promptly, whereas female patients took longer to decide for lifestyle and went through a nexus of cultural complexities. A study (Pond, Sturock, & Jeffcoate, 1996) also discussed the quality of diabetes control that may be considered consistent with current study. The female gender was found to be worse in all ages than male gender. The study also suggested that this gap is because of double weight of coping the situation for female diabetics (as managing diabetes and also taking care of their families). Also a study in Germany, conducted by (Raum, et al., 2012), found gender specific differences in association of adherence and glycemic control (women were found to be more non-adherent due to certain overwhelming responsibilities).

The hidden barriers and unseen priorities for female patients may be found as an important area of address for the public health service delivery. The female patients were overall prioritizing the lifestyle of their respective families (that may change with the

number of children, support of/by parents' in-laws, financial situation of the head of the house, structure of the house, ethnicity and sect). It may be considered similar with the findings of a study (Martz , Handley, & Eisler, 1995), which has stressed upon the traditional sex roles of females that may be seen as a hidden barrier to the adherence towards the proposed treatment. The related issues discussed in the same study were found consistent with the current study, where the willingness of female patients was deeply compromised for not changing her lifestyle due to meeting the demands, needs, and taste of her respective families. The support of the family was also found to be a barrier that may be considered directly proportional to the adherence level and commitment.

Gender holds a significant dimension in the episode of diabetes, and was found to influence, mold, and shape the directions of each stage (as discussed in the results chapter). The most important stage was the decision of treatment, and then adhering to the treatment plan(s) that may compromise due to the above mentioned factors (visible and hidden).

The perception towards treatment was influenced greatly by the concept of curability of the said disease. The respondents kept seeking treatment that may diabetes. All of the respondents did try the *Chak Mangla* water and certain home based remedies in a quest to overcome the daily management of diabetes. The proposed treatment was delayed and compromised in understanding, coping, verifying and learning the process (of clinical management and adhering to required lifestyle modification).

The treatment was considered complex (especially after the initial counseling session), and led patients' to explore support and alternate treatment (support and alternate treatments are usually endorsed and advertised communally). Complexity was burdened in understanding the lifestyle modification(s) through flip tool messages (though it was delivered in the local language and dialect). The counseling session leads to many complex questions related to the cultural context of the respondents. The 'lifelong management' itself created many complex questions, in and towards the perception of long term treatment (of/for diabetes). It may be found consistent with existing studies that

reflect a strong relationship between complex treatment and patients' adherence. The complexity (number and timings) in prescribed drugs (Horne & Weinman, 1999) (Patal & Taylor, 2002) (Grant R. , Devita, Singer, & Meigs, 2003), and treatments (Kass, Meltzer, Gordon, Cooper, & Goldberg, 1986) (Cockburn, Gibberd, Reid, & Sanson-Fisher, Determinants of non-compliance with short term antibiotic regimens., 1987) (Cramer, Mattson, Prevey, Scheyer, & Ouellette, 1989) (Eisen, Miller, Woodward, Spitznagel, & Przybeck, 1990) (Cramer, Enhancing patient compliance in the elderly. Role of packaging aids and monitoring., 1998) (Sung, et al., 1998) (Claxton, Cramer, & Pierce, 2001) (Iskedjian, et al., 2002), were found to be an important dimension affecting adherence to the treatment in a negative manner, as found and discussed by above mentioned studies.

The pilot intervention's registered patients (and this study's respondents) were newly diagnosed, and may be considered as a reason towards shabby adherence to the proposed treatment, it is also consistent with existing research studies that have found that longer duration (of chronic disease) may result in better compliance and adherence, as discussed by (Sharkness & Snow, 1992) (Garay-Sevilla, et al., 1994). Newly diagnosed patients had poor and low adherence was also found by (Caro, Salas, Speckman, Raggio, & Jackson, 1999). The denying of disease (due to new diagnosis) was found to be at a higher end that also caused a strong desire for the cure, and seeking early benefits as a priority in seeking other treatments (including support, alternate and spiritual treatment).

The desire for cure, early and maximum benefits were the major reasons for explore and use of home based remedies, support treatment, spiritual treatment, and also alternate treatment. The support treatment (of *Chak Mangla* water) was found to be an interesting dimension as it does not affect the adherence to medication (drugs), but influences negatively the lifestyle (i.e., diet, exercise and smoking). The support treatment relaxes the patient in a way that they start desiring for an early benefit and start compromising on adhering to the diet and exercise (in few cases). The medication, however was not found to be negatively influenced by the use of *Chak Mangla* water. All of the respondents were also found trying home based remedies along with allopathic medicine (as given by the



RHC). The home based remedies included bitter herbs juices (mostly boiled in hot water) taken early morning (empty stomach). The paramedic did not consider it harmful, and considered it as a positive support (according to him it is just water) when shared by a few patients (in the follow-up sessions).

The discussion above may be found consistent with existing literature reflecting reasons for frequently using supplementary or complementary medicines, spiritual treatment, and alternate treatment in case of diabetes. The reasons found in an earlier study by (Mehrotra, Bajaj, & Kumar, 2004) were early and maximum benefits; the current study, however, found an additional reason (e.g., cure) as an addition to early and maximum benefits through supplement and alternate treatment options. Other studies support the current study's arguments of frequently usage of home based remedies (especially bitter herbs), support treatment (therapies such as massage, hot tub and acupuncture), spiritual treatment (including yoga and prayers), and alternate treatment (such as Ayurvedic medicines and treatment) for their diabetes as discussed by (Singh, Singh, & Gautam, 2012) (Sushama & Nandita, 2012) (Chacko, 2003) (Dham, Shah, Hirsch, & Banerji, 2006) and (Sethi, Srivastava, & Madhu, 2011). The current study also suggests the health care providers (at RHC), to take into account, support or complimentary treatments (that may be considered as positive agents in achieving both parts of treatment i.e., clinical treatment and lifestyle modification). The herbal treatments, in combination with proposed treatment, may be further explored (in the dimension of creating hypoglycemic agents).

The diabetes was not found immediately painful by the respondents, nor was it found creating any barrier or compromising ability (as all of them were newly diagnosed). The respondents were less explicit about the diabetes as compared to adhering to the proposed treatment (especially adhering to the suggested diet and exercise). The respondents were less concerned in case of achieving active follow-up due to no immediate pain or discomfort. The personal and social life pressures forces the respondents to calculate the treatment (that is less demanding and offer maximum benefits). The family support was also found to be important in achieving better adherence. This includes the ethnicity,

education, belief system, and financial background of the family. Family not only decides for the treatment, but also towards the adherence (of that treatment). The female patients were found to be more dependent on the collective decision towards proposed treatment (and its adherence) at the RHC. The complex nature of diabetes, especially regarding the severity of pain and discomfort, may be considered as a major factor (as the daily activities were prioritized by the respondents) and lead to poor compliance. The pain was found to be directly proportional in seeking active health care and treatment (especially from the public health facility). The pain along with visible physical symptoms were found to be an important dimension in demanding family support (both explicitly and implicitly). The conceptualization of pain (as a diabetic) is consistent with an earlier study (Tripp-Reimer T. , Choi, Kelley, & Enslein, 2001) that lead to the demand of family support (Lawton, Ahmad, Hallowell, Hanna, & Douglas, 2005).

### **8.3. Patients' explanatory model and adherence**

The conceptualization, representation, and practices regarding type 2 diabetes at patient's end was found significantly important, and also explained different stages of the illness that included progress in terms of diagnosis, labelling, treatment, and adherence towards the treatment. The adapted explanatory model did help understand the process of the decision making, especially in choosing and evaluating the treatment(s). Both the social construction and implicit cognitive understandings of the said illness were found to address the cultural gap in the implementation of the pilot intervention that is also in the process of province wide upscale. The role and importance of explanatory model was found of great significance in understanding the compliance/adherence to the offered treatment(s), and may improve the communication between the care provider and the patients, as studied and explained by (Barsky, et al., 1980), (King, 1983), (Garrity, 1981).

The present study found that the perception of the respondents towards their illness was more of a cultural and religious construct. Most of the patients did relate their illness with death of a relative, stress episode, and financial issues. It was also inferred that the patients actually did relate the appearance of illness with a strong wave of depression, sadness and feeling of loneliness. Same as the case with the time and mode of onset,

which was heavily expressed with the start of the episode of grief, or after the realization of a loss. The grief incident was found to capture the main frame of the time and mode of onset of the illness. The patients generally described their respective time and mode of onset as in terms of after the loss of a family member, along with exact description of day or night, and month (usually expressed in the Punjabi calendar terms). The realization of the illness with specific time and mode of onset was mostly religious and cultural for example, not able to complete/fulfill the religious obligations especially daily prayers, or loss of stamina especially in case of not coming up to the daily tasks and daily house chores (in case of most of the female respondents). The respondents were found to go through a number of opinions before reaching the public health facility for biomedical diagnosis and treatment. The initial discussion were done domestically and communally, especially with existing similar symptoms, cases, and reachable community based options. Most of the respondents did trust the diagnosis and label (as a diabetic) by the public health facility (bio medicinal method), but varied in terms of adhering to the offered treatment (i.e., the clinical treatment and lifestyle change). The respondents did rely on a number of treatment methods as shared in the previous chapters, including support treatment (i.e., *Chak Mangla* water and home based remedies), and alternate treatment (i.e. Hakeem and Holy man). The perception towards the curability of the illness greatly influenced the adherence to the offered treatment and management of suggested lifestyle modification. A similar study was conducted on patients seeking treatment in Addis Ababa and Butajira, Ethiopia, exploring the different perspectives of patients of diabetes 2 in order to design effective strategies for them to manage the illness. For this, Kleinman's explanatory model was used, and the data was collected through qualitative interviews based on the model. This study is consistent with the findings of the current study. The results showed that the perceptions of the patients were influenced by their religious and cultural values. Many patients were uncertain of the causes of diabetes, although after interviews and discussion, it appeared that heredity and emotional causes, such as anger, rage, being upset etc. were the most common among them. Many of them perceived and related their time and mode of onset of diabetes and the starting point of their illness, with long term grief and being startled, an episode of emotional event, or sudden rage. Patients locally described different symptoms that led

them to health care seeking, most common of which were weakness and weight loss, and increased thirst and frequent urination. Strong emotions were also expressed after being informed of diabetes, such as being upset, startled and hopeless. Some patients were not able to understand the chronic nature of their illness, and thought that it was acute in nature, and would be cured if treated. Whereas, some thought that it was a fatal disease that would cause them death shortly after its occurrence, and assigned themselves with a permanent sick role. Most of them comprehended the chronic nature of diabetes after their long-term experience and dealing with the disease, as well as after seeking explanations from the health care providers. As for the treatment, people sought biomedical treatment, traditional medicines, and religious healing. Some believed that the biomedical regimens could control the disease, while others thought that they could be a source of cure if recommendations such as medications and diet patterns were followed. Christians used holy water and prayers as a source of religious healing in managing and curing diabetes. Muslim participants adhered to prayers, in order to cure diabetes. For traditional medicines, medicinal plants such as shiferaw, anamuro and koso areqi were mentioned to be used, that benefitted them in the control of sugar level. Lifestyle management, with lives free from, or with controlled negative emotions were also considered as ways of curing or managing diabetes. (Habte, Kebede, Fenta, & Boon, 2016)

Another study was found to be consistent with the dimensions of adherence to the offered treatment and management of diabetes. The respondents in the present study were cure driven, and were able to experiment due to the monotonous nature of pressurizing life style change, and clinical treatment (especially follow up visits). Whereas, a study in rural town of Taiwan showed that diabetes was considered to be caused by the over utilization of foods with high level of sugar, or through inherited genes. Therefore, it was deemed as a 'disorder of sugar metabolism'. The most mentioned complications of diabetes included renal problems, leg amputation and blindness. People described it to be slow and torturous. A unidimensional manner was observed in the pathophysiology of diabetes, and it was considered to progress in steps. Some people thought that higher level of sugar will lead to greater number of medications, which will result in high blood

pressure, and eventually stroke, while some considered strokes to be an unrelated disorder. Some believed that medications will be followed by insulin shots, then dialysis, and then death, in steps. The description of the course of illness varied. Many patients believed that diabetes is incurable, and their temporary treatment was to control their sugar level only. Some were really concerned with the long-term chronic complications of diabetes. They perceived the severity of their illness by measuring their health status at a certain point of time, on daily basis, or through the medications they used. They believed that larger dose means more severity of their illness. Similarly, usage of insulin injections was linked to death, for being an indicator of severe diabetes. People sought pharmaceutical drugs for treatment. Many patients did not adhere to their treatment due to the perceived unidimensional nature of diabetes. Some hesitated, or rejected taking high doses, because they thought that it was only an indicator of the severity of illness, and that it would result in a vicious cycle of drug taking, resulting in addiction. (Lai, Chie, & Lew-Ting, 2007)

On the other hand, a study in the United States, regarding the self-management of hypertension was found to be influenced by the larger culture of USA, and also specific ethnic culture of different respondents. The sample was selected from African-American, white, and Latino patients, as hypertension is a major and prevalent problem in USA. 20 patients were selected from each ethnic group, in a one year duration from two U.S. Veterans Affairs Medical Centers. Semi-structured interviews were designed, recorded, and transcribed to collect the data. The data was deciphered into the five categories of the explanatory model (EMs), and their social contexts, or the Daily-Lived Experiences (DLEs). The patients occasionally deemed pathophysiology to be unnecessary in describing self-management behaviors, while other episodes were frequently linked. The patients listed two types of causes to both chronic hypertension and temporary increase in BP, among which inheritance, stress, exercise, and poor diet prevails. Their self-management behavior was to avoid conditions of stress to relieve hypertension. The patient's perspective about their course of illness was somewhat ignorant, which made them skip medication, or take medications at times only, as a self-management behavior. Some stated that there were no definite symptoms, and only took medications when an

issue was sensed. Others listed symptoms such as headaches, chest pains, and altered self-management behaviors accordingly. Regarding effective treatments, patients were willing to frame their self-management behavior by taking pills, relevant diet, and relaxation as well. Others would only opt for exercise to relieve hypertension, and consider pills as unnatural. Self-management of hypertension was dependent upon their Daily-Lived Experiences, which included five categories that influenced their EMs. Some patients were unemployed, resided alone, and went to dinners for socialization. Hence, they couldn't skip sodium as a part of their DLE, which was detrimental for hypertension. Another DLE included being possessed by other illnesses, which made hypertension relatively less important to be treated, or perform other recommended activities. This affected their EM of hypertension by considering it as symptomless as well as unimportant. Other patient's DLEs included irregular routines making them forget their medication intake, and imprecise jobs, prompting them to have inappropriate diet for hypertension. This inhibits his EM of taking a less salty diet. Unsafe environments and treatment patterns for other illnesses also affect the EMs of hypertension. Patients also prioritized their personal likings over medications, such as drinking, and put forth their EM by intending medication to be a weekly doze rather than a daily one. It is, thus, evident that DLEs and EMs of patients interfere in their self-management behaviors, resulting in the framing of Dynamic Model of Chronic Disease Self-Management, in which the EMs and DLEs frame each other throughout the tenure of the illness, relative to the behavior. The patients believed it important to consider the patient-provider communication for their self-management, thus, it is included as an important element of the model (Bokhour, et al., 2012).

The patients' explanatory model did bisect the stages as an episode of the said illness. Each stage was found to be socio-cultural construct ranging from their personal perceptions, expressions to the social manifestations. The model also found that the pre diagnosis stages were heavily influenced by a number of opinions, and lay beliefs regarding the early symptoms of diabetes. The process of getting it diagnosed was also found to be domestically and socially discussed in detail. The diagnosis and registration of the patients reached up till three visits (in a few cases) and two visits (in most cases) as

the respondents had their own understanding for fasting blood glucose test. It was also found that acceptance towards the labelling (as diabetic) was cross verified, and the fate of adherence varied from there onwards. The follow up visits did vary due to certain socio-cultural factors as discussed above. Nearly all of the respondents at least once tried the *Chak Mangla* water (with a hope of getting cured), but it did not hinder the clinical treatment, but affected the lifestyle changes suggested (in a few cases). The *Chak Mangla* water was considered as an added benefit alongside bio medicinal treatment. The respondents found the *Chak Mangla* as an enhancer (in most cases) to cure diabetes, as a motivator (in few cases) to manage diabetes, and suggested opinion (in a few cases) that may be used, but may not cure (or hinder in visiting for monthly follow up).

The other treatments as shared by the respondents proved to bring benefits as a social package for example, in case of a divorcee it is culturally endorsed, religiously accepted and financially viable. The mobility is less challenged when the treatment turns in to a spiritual treatment. On the other hand, nearly all of the respondents did also share number of home based remedies used in different fashions and methods. Hakeem may also use *Melia azedarach* L. with common names as dherak, chinaberry by using the leaf and fruit of it for diabetes mellitus and also as blood purifier. The common wisdom was found that in order to kill the sweetness in the sugar (sugar is also a common name of diabetes), one may use plants (in shape of juice or boiled) that are acidulous. However, the sweet was considered as more of white sugar, and brown sugar was not considered as dangerous for diabetes. Same as the case with brown sugar related sweet dishes.

The post diagnosis and labelling stages involved much in exploring various methods/treatments that are culturally endorsed and easy to comprehend. The comprehension increased the probability of relying on the particular treatment (as it was easy to remember, and part of the routine and the method of application was also in local terms and language). The adherence to the treatment (here pilot intervention) was greatly influenced by other treatments (support and alternate) that were found easy to comprehend, thus easy to adhere in terms of ability, skill and finances. Most of the

respondents did not consider diabetes as severe and may be cured with the passage of time and finding a perfect traditional cure for it.

The lifestyle change (as part of the offered treatment) was also found to be an important aspect influenced by various socio-cultural factors. Both time and space was found to be influenced by various factors (as discussed above and in previous chapters). The diet, exercise and smoking were all found to be challenging, and may troubleshoot locally, or with local examples. A study revealed that diabetes made the patients to change their illness behavior by opting for food items different from their local routines, re-budgeting the household expenditures, and limiting participation in social gatherings due to fatigue and frequent urination. (Metta, 2016)

The model did explain the entire episode and how different actors and acts were played during different stages. From pre diagnosis perceptions to the influencers in adherence to the treatment may be considered as a journey that may be useful for the local physicians and doctors (primary health care level). The model explained the various factors, and have also identified the directness, and prioritization that may be taken into account during the well segmented biomedical stages in the diagnosis and treatment of type 2 diabetes (the desk guide is Annexure).

The present study has also suggested that a sub stage/theme in similar context researches may be further added that may account the adherence to the treatment. Here it is important to mention that biomedicine as becoming central theme in treating major diseases globally, may be required to understand with an additional dimension to treatment (within classical explanatory model). By adding a sub dimension with treatment, a passage may be made to contextualize the tug of war between biomedicine and socio-cultural factors. The adherence to the treatment may also open fresh debate and troubleshoot frameworks in managing the known/registered cases. The contextualization through explanatory model did help understand the issues related to/with gender especially. The issue of being a Punjabi woman when diagnosed and labelled with diabetes, the misperception of gaining infertility with diabetes though it is also believed



that it may be cured. The perception however remained fixed with losing physical and mental stamina and sexual strength.

The adapted model is explained below, how each stage brings certain socio-cultural factors as enablers and disablers towards adherence to the treatment offered through RHC (as a pilot intervention). The adapted model did provide a continuum of the journey starting from the perceptions and processes of diagnosis till treatment and adherence to the treatment. The perceptions towards the cause of diabetes were found to be an important dimension that may set the pace towards exploring opinions and exhausting them one by one keeping in view the gender, age, finances, ease and reach. The factors both worked as enablers and also as disablers in each stage of the adapted model. The perceptions of the cause of diabetes was also translated in the interpretation and recalling of time and mode of onset of the said illness. The pathophysiology and severity was also mostly opinionated as designed, crafted and constricted to a few socio-cultural definitions and expressions.

The treatment was found to be an amalgamation of various factors (as discussed above and in previous chapters). The follow up visit (as suggested), found to be compromised due to certain factors including opportunity cost, perception towards the public health service delivery and the perception towards the curability (timely or permanent), did force a reasonable number of respondents to explore other available methods. The support treatment did not directly hinder the biomedical treatment whereas, the alternate treatment did offer a complete package. The alternate treatments were found to sell itself based on its comprehension, local terminologies and access.

The lifestyle change may also be considered very complex especially in case of changing diet and incorporating exercise in the daily routine. The diet was heavily influenced by the position/status in the family, gender, season and cultural perception of what is healthy and what food is medicinal or not appropriate. The exercise was found to be an emerging concept in the realms of physical activity of the said community.

**5a: Factors influencing/affecting adherence to the clinical treatment**

- Public health service delivery
- Opportunity cost
- Perception towards curability
- Gender

**5b: Factors influencing/affecting adherence to the lifestyle change**

- Position/Status in the family
- Cultural perception of healthy diet
- Concept of physical activity
- Gender

**1: Cause of Diabetes**

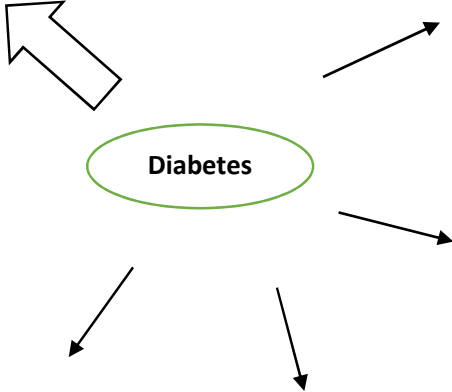
- Stress, trauma
- Death (family member or relative)
- Financial Loss
- Inheritance, property issues

**2: Time and mode of onset**

- Funeral
- Traumatic episode

**5: Treatment**

- Processes before reaching RHC
- Diagnosis
- Adherence to Follow up
- Support/Supplement treatment
- Alternate treatments

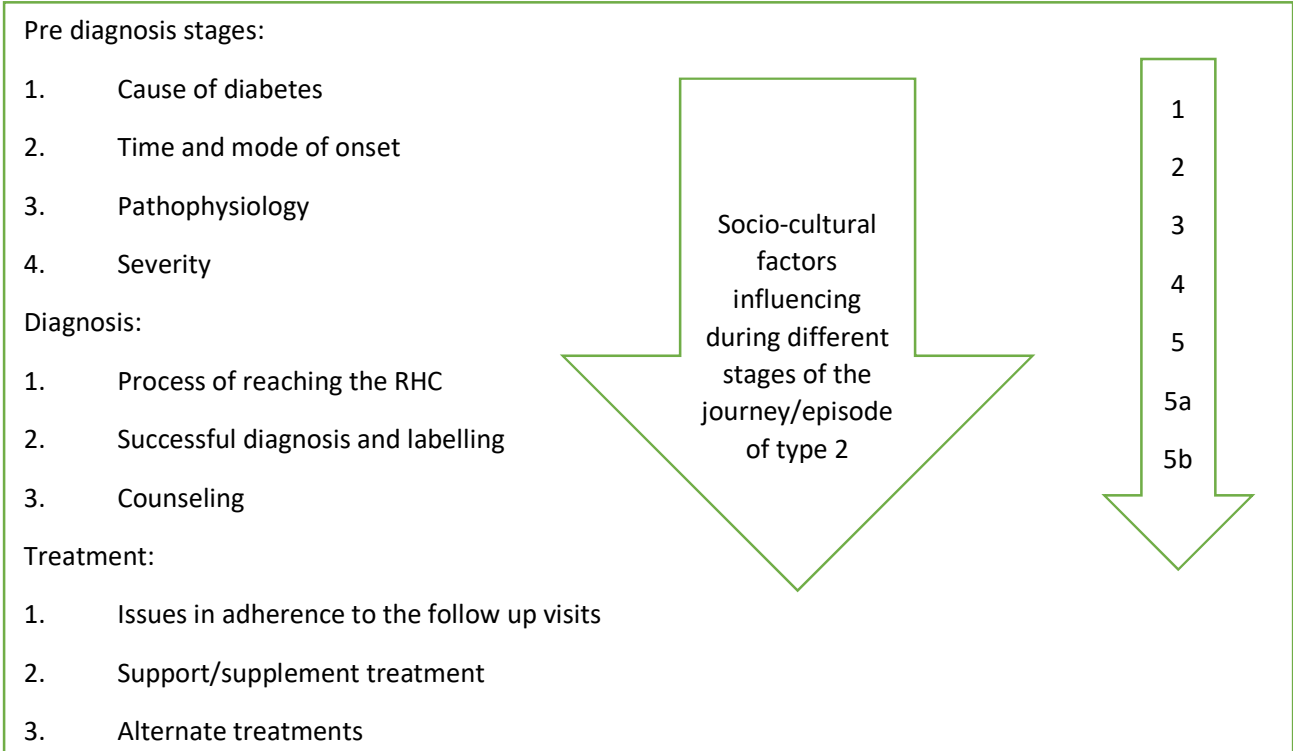


**4: Severity**

- Temporary (in most cases)
- Curable

**3: Pathophysiology**

- Weakness (Khali, Kamzori)
- Loss of stamina
- Fatigue



The model sketched above describes three major episodes within the journey of the said illness. The first episode was mostly about lay perceptions, domestic and community level consultations, identification and interpretation of the symptoms. The first episode was an amalgamation of cross verifying the general perceptions from the family and related community members. The symptoms are interpreted locally and referred to available options for the treatment. This episode converts into another episode in this scenario with processes that lead to getting diagnosed from the public health facility. It is also important to mention that the educational background and financial situation of the registered patients forced them to restrict to explore local treatments and may jump to a public health facility. This episode also found that the respondents did trust the diagnosis part from the public health facility, and did accept (after cross verification and consultation) the labelling as well but explored various methods instead of adhering to the proposed treatment (i.e., clinical treatment and lifestyle change).

The third episode shaped the journey of diabetics towards exhausting different treatments. The biomedical treatment adherence was however greatly influenced by the economics of the household, domestic hierarchy, perceptions towards curability of diabetes, and the gender of the patient. The influencers are not limited to the above mentioned, and affected the adherence to the clinical treatment, both in a combination of direct factors and in-direct factors. The clinical treatment and suggested lifestyle change was found to be a complex process to routinize in the daily life of the respondents. The space of the house(s), the landscape and space division of the village, the concept of time and physical activity and culturally healthy food, all played a vital role in the adherence to the suggested lifestyle modification.

The adapted model suggested a road map that may suggest the understanding of the processes involved for reaching the health facility, experience of getting diagnosed and labelled and acceptance of that label, issues in routinizing the treatment (i.e., clinical treatment and lifestyle change), and how certain socio-cultural factors influence the adherence to the suggested treatment. The present study may add to the existing frame work by adding a sub dimension within the existing dimensions of the model.

The patients' explanatory model as discussed in the literature holds a significant application in understanding the five major dimensions, however this study indicates that a sub dimension may be added in the existing model that may reflect understanding on factors/influencers in compliance/adherence to the treatment of type 2 diabetes.

The adapted model suggests the Ministry of National Health Services Regulations and Coordination in general, Non-Communicable Diseases and Mental Health Programme in particular to improve the patient provider communication at the scale of Punjab province. Also adds to the training of the physicians and paramedics of the primary health care in Punjab. A refresher training may add anthropological finding with a special focus from the present adapted patients' explanatory model. The findings of the present study may open a wider understanding in the process of design, and conduct outreach health education of/for diabetes in the Punjabi rural areas. The reminder regarding the scheduled follow up visit may be designed in a more structured manner, also will be easier for the health staff to take into account other equally important situations (at patients' end). The importance of gender, age, economics, opportunity cost, domestic hierarchy, lay understanding and perceptions of physical activity, sweet, food may all be used as influencers in the implementation of the diabetes care.

The present study also managed to explain the issues that may be relevant in diagnosing, labelling and achieving better adherence. The role of paramedic was also found to be important indeed, that may not only differentiate the issues at the patients end but also suggest/guide them in local context. The reminder call to the patients or treatment supporters for required follow up visits by the paramedic now holds range of backgrounds to be taken into account.

The programme may also construct a framework to identify ways to incorporate issues that demotivates a patient towards adherence. The opportunity cost along with detailed costing studies may add further dimension in the understanding of adherence. The counseling of treatment supporter along with the patient may also be considered as an important point, as most of the patients were found to visit as a group of family members. It is also important to mention that this practice may be found important, especially in

case of female patients, whose position/status in the family makes them at the lower end of the domestic hierarchy.

## 9. SUMMARY AND CONCLUSION

The diabetes is a multifactorial disease that not only demands clinical support, but also a fair deal of understanding of the socio-cultural factors that may lead to the design and implementation of better prevention and effective management (of the known cases). The 'National Action Plan' of non-communicable diseases placed diabetes as a major burden to the national economy that may be translated in the household economy (especially in the case of rural areas of Pakistan). The lifelong management of diabetes may be seen and educated as a complete shift in the lifestyle and the socio-cultural construct of the disease (that is commonly known as 'Sugar'). The diabetes care package includes beyond clinical management of the patient including diet, exercise and smoking. The other important details include the management of the prescribed drugs, attending scheduled follow-up visits recommended by the public health facility, discussing issues in the counseling session(s), and remain vigilant and agile towards the general care of the body, infections and wounds.

The present study explored the socio-cultural factors affecting the adherence to the proposed treatment of type 2 diabetes implemented as a pilot intervention on the selected health facilities (in district Sargodha). The locale of the study was the catchment area of 'Rural Health Center 104 North Bound'. The health facility was able to identify and register 71 patients without any outreach through normal/routine check-ups. The locale did outnumber (in terms of patients' registration), other selected health facilities (as part of the pilot intervention). The female patients were comparatively more in number as compared to the male community members. The care package offered included clinical treatment further divided into three major components including diagnosis (and label), prescription and drugs, and follow-up. The care package also offered life style modification through trained paramedic (in style of counseling session) to the registered patients. The life style modification part included messages on diet, exercise and smoking (as they are most relevant to the effective and efficient management of diabetes).

The Punjab (especially rural Punjab) is often associated with taste preferred diet (both food(s) and drinks). The changing climate, emerging industrial economic behavior,

traditional perceptions towards illness and health, and technology induced information have made new layers of cognition(s) and practices, bringing a complex lifestyle (that has mostly affected the taste, physical activity, and also desire for cure/maximum benefits in case of getting ill) in Punjab. The above mentioned dimensions not only affect the diet patterns, but also the perceived seriousness towards active health. Thus, the adherence to the proposed treatment of type 2 diabetes does demand beyond clinical exploration to inform the action plan in general, and strategic in specific, to design framework(s) of prevention and known case management. The patients' perspective(s) towards the adherence may be found most vital and important as it has identified gaps, and also found answers to fill it in the current study. The understanding of the context have also added to the effective and efficient design and implementation of diabetes care package.

The adherence to the treatment is indeed an important dimension, especially in the management of the non-communicable diseases, especially diabetes. The compliance to the scheduled follow-up visits, prescribed drugs, diet, exercise and smoking, is an integral part of diabetes care (in specific). The proposed care was found to be translated in more of a social and cultural fashion, such as diet (with all of its recipes and arrangements) that may be opposite to the proposed healthy diet. Same as the case with the concept of lifelong management that may be seen contrasting with existing conceptualization of illness (that may be cured instead of getting managed). The quality of the public health service delivery also plays an important role towards adhering to the allopathic medication and treatment. The physical activity was also found to be different as compared to the proposed exercise, as part of the daily care of diabetes. The patients' perspective may be seen and graded as a powerful notion towards the proposed and implemented care at public health facility.

The clinical treatment (i.e., diagnosis, medication and follow-up visits) was found to be influenced by patients' perceptions regarding the cause of their diabetes, time and mode of onset, pathophysiology and severity. The diagnosis was found to be a complex process, (as most of the respondents did exhaust available options before reaching the public health facility). The medication was also found to be influenced by certain

perceptions, including the quality (of the medicines given by the RHC free of cost), and quantity of drugs. The follow-up visits were found to be affected by a number of socio-cultural reasons, including desire for cure and maximum benefits through treatment (as the proposed treatment suggests lifelong management instead of cure), culturally endorsed support treatment (*Chak Mangla* water), and home based remedies (mostly used to cure or reverse diabetes instead of managing it), alternate treatment (that advertises the cure for diabetes). The clinical treatment (especially the component of scheduled follow-up visits) was overall affected by patients' perspective towards the public health care service delivery (including the timings of the RHC). The role of paramedic was, however found positive that may with active involvement keep patients to make follow-up visits (for recommended check-up), get medication, and discuss lifestyle related issues (during the counseling session).

The lifestyle modification was also greatly influenced and affected by certain socio-cultural factors. The patients' perspectives towards diet, exercise and smoking was also found to be a complex socio-cultural construct. The concept of healthy food, physical activity and smoking was strongly influenced by cultural practices that have been an integral part of the traditional wisdom. Certain food recipes are cooked and carried as a family tradition (used as a taste preference and also medicinal value). The use of oil, salt and sugar was also found to be taste driven, and may not be considered unhealthy by the respondents. The division of daily meals, work distance, position/status in family and gender were found to be all important factors that may contribute towards low adherence to the proposed diet. The proposed exercise was contrasting with certain factors including the appropriate space for exercise, allocation of time for exercise and gender. The female patients were found to be mostly non-adherent towards the physical activity, and also confused it with house chores (as there is no concept of calories count and management). However, a few educated patients (especially male) were found to cut down meal portions (both chapatti and gravy), and also less use of (mechanized) transport to commute for daily work (by that way interpreting some control on diet and also physical activity). The smokers did not appear significantly as per the registration data (hence comments may not be generalized).



Certain general factors were also found to be cross cutting towards the major stages of the entire episode of diabetes. The diabetes was both horizontal and vertical in terms of its conceptualization, and were found to be greatly influenced by religion, ethnicity, perception of/towards spirituality and environmental factors. It was interestingly found that the age was also a rich cultural category (and was not perceived as it is normally perceived in clinical sense). The education and health literacy was heavily loaded with the concept of cold and warm, heavy and light, ill health and cure. The conceptualization of health overall shapes the care seeking behavior as found in this study. The cold must meet warm (and was translated in food, activity and medication), the heaviness may be converted towards light, and same as the case with the concept of ill-health that may meet cure (instead of management). This socio-cultural construct of health, cure, diet, exercise and smoking affects the overall adherence to the proposed treatment.

Though the pilot intervention was thoroughly designed to be implemented through primary health care facilities, patients' perception(s) towards quality of health care service delivered through public health facility, was found to be not satisfactory (in general). The adherence to the scheduled follow-up visits was generally compromised due to the morning timings, access, opportunity cost (per visit), long queues and no promise of getting cured (for diabetes). The perceived seriousness of/towards diabetes also added to the initial non-adherence towards the follow-up visits. It may be concluded that certain cultural channels and platforms may be exhausted by the patients before getting diagnosed, after getting diagnosed and labelled, and at least three months of not accepting being a diabetic. These three months are usually consumed with consultations at domestic and certain social gatherings, including taking opinions from previously diagnosed patients (as diabetics), extended family members, quacks, and advertised, and culturally endorsed other treatments. It may be concluded that since there is no immediate pain in diabetes that may also lead to non-seriousness towards allopathic treatment (at public health facility). Certain other methods were exhausted in the newly diagnosed patients (in the study locale) in a few months after the diagnosis (and label). A detailed strategy may be developed to convince the diabetics regarding the seriousness of the diabetes with the diagnosis and label. First three follow-up visits may be promoted (with

repeated reminders through phone calls and a standard text message in the comprehensible language).

The national programme may also focus regarding the strong gender divide in the perception, comprehension, and adherence towards treatment. The socio-cultural construct of the gender (especially female gender), may be concluded as an important dimension to be taken in account (of/for the diabetes care package). The gender in the current context (of the locale) was found to influence the domestic hierarchy upon which certain decisions are made, or taken independently, or as a subordinate. The female gender may be considered as an important distinct category that may be educated with a special context (with their domestic hierarchy, and even gender hierarchy in the household). The adherence to the diet and exercise may be concluded as a comparatively harder tasks for the female gender (especially as a wife in the presence of mother in law). The mother in law and husband (of the patients) may also be considered as a potential treatment supporter (that may be educated, keeping in view the cultural sensitivities). The paramedic(s) may be trained in a way to address this cultural reality (of gender hierarchy), to be educated for the process of decision making regarding the treatment (and lifestyle in specific). Also a pool of alternate culturally competent suggestions/recommendations may be designed to be provided (to the patients and treatment supporters), through the counseling session(s).

The support treatment (*Chak Mangla* water) in this case may not be considered as a threat to the clinical treatment (especially the drugs), but may adversely affect the adherence to the proposed diet and exercise. Support treatment and home based remedies may be concluded as a positive push towards seeking the treatment (from a public health facility) for diabetes. The support treatment may be considered as a culturally endorsed practice that may help patients' to seek the proposed treatment (with an additional desire of getting cured over time). If the support treatment or home based remedy is not a threat to the glucose levels, then it may be concluded to use it with existing treatment with a psychological satisfaction (for patients) as it is managed at home, and found to be culturally and economically comprehensible.

The scheduled monthly follow-up visit(s) may have both travel and opportunity cost involved for the patients. The patients calculate cost directly for travel (to the health facility), and opportunity cost as an in-direct cost (as an arrangement of accompanying person in case of female and elder male patients). The opportunity cost also included taking a day off from work/business (in case of male patients or as an accompanying person). The cost of change in dietary and exercising practices is not significant for most of the patients. However, diabetes patients do need to cope with a range of socio-cultural challenges, and barriers for influencing their families, and get their (family) diet modified, and practice the daily exercising. This is an area where further qualitative research can help designing contextualized life style modification interventions.

It may be concluded that diabetes was found to be made up of certain socio-cultural perceptions and practices. The adherence to the treatment (clinical treatment and lifestyle modification) was also found to be a strong socio-cultural construct. Certain factors were found to greatly influence the episode of diabetes (as studied with the help of patients' explanatory model). The participant observation(s) and in-depth study of the phenomenon may suggest/recommend the national programme to take in account the beyond clinical understanding, realities, barriers and also enablers. The adherence to the treatment may be improved with the help of understanding (in-depth) the patients' perspective that may lead to develop culturally competent strategies, to troubleshoot barriers at the important stages of the diabetes (especially diagnosis, label, prescription, follow-up and lifestyle modification). It may also be concluded that the range of health care providers (as explored in the study) may be considered as important stakeholders in the different stages of the disease. The incorporation of these health care providers in the general framework may help educate and refer (the patients) in case of emergency, and complications (to the RHC).

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# GLOSSARY

## Chapter One

**Chak** An agricultural field, also known as a village. The villages are named using a certain nomenclature that dates back to British rule; all names are prefixed "Chak" followed by a number and a letter. The number is the name of the village and the letter relates to their source of water.

**Shumali** Northern, Northbound

**Urdu** Urdu is the national and official language of Pakistan. It is written in a modified version of the Perso-Arabic script, and written and read from right to left. It is an alphabetic script whose letters include thirty-three consonants taken from the Persian alphabet, as well as three new letters that represent retroflex sounds, and eleven compound letters that represent aspirated consonants.

## Chapter Three

**Dera** A tent, or a camp. Dera is a sitting place mostly for the male members of the Pakistani society. Dera is a generic term for the camp of a saintly figure located outside the influence and territory of the social space of a community. Its origin in Punjab could be traced back to the Nath tradition of Gorakh Nath. Deras substantially differ from each other in terms of various traditions, beliefs, and practices.

**Shahpuri** Shahpuri dialect (also known as Sargodha dialect) is mostly spoken in Pakistani Punjab. Its name is derived from former Shahpur District (now Shahpur Tehsil, being part of Sargodha District). It is spoken throughout a widespread area, spoken in

Sargodha and Khushab Districts and also spoken in neighboring Mianwali and Bhakkar Districts. It is mainly spoken on western end of Sindh River to Chennab River crossing Jehlam River.

#### **Chapter Four**

Asar	The third prayer, that comes in the afternoon and after the Zuhr prayers. In the afternoon or midway between noon and sunset, when the worldly involvements are at a peak, the third prayer of four units befalls the believer
Atar e Gulaab	Rose flower extract, juice/essence of the rose petals
Azaan	The call to prayers; Azaan is recited five times a day, summoning people to offer their daily prayers.
Baba	The word ‘baba’ is highly respectful title for an enlightened, pious, irradiated person who sacrificed his personal gain and loss notion over non-material objects that are God, manhood, self-purification, etc. This word generally denotes age, knowledge, righteousness of a person. It is also commonly used as a term of address for old men.
Bahaar-Aai	Coming of spring, celebration of spring season
Baithak	It literally means seat or place to seat, place to seat the male guests (especially in case of Punjabi Baithak).
Baluchistan	Baluchistan is the land between south-western Pakistan, south-eastern Iran, and a very small section of south-western Afghanistan. Baluchistan constitutes 44% of Pakistan’s total area. It is one of the four provinces of Pakistan, and is strategically

extremely important to the country because of the high concentration of natural resources including gas and oil.

**Bantay** Marbles; also known as Kenchay or Kanchay, is a traditional game locally played by the children in rural areas of Pakistan. A pit is made to score the bantay in it and is usually played by two players or two teams comprising of two members each.

**Baraati** A group of people from the groom's side, including the bridegroom himself, in traditional Pakistani marriages, who process to receive the bride and bring her to the new home after marriage on the second day of the marriage festival, that is the Baraat.

**Barelvi** The Barelvi is a revivalist movement created by Imam Ahmed Raza Khan Barelvi in the late 1800s, which played a decisive role in the renewal of Islam in modern India. The name Barelvi comes from the native town of Ahmed Raza Khan of Bareilly in North India. Often, they prefer to be known by the title, the Ahle Sunnat wa al- Jamaat (the People of the Sunnah and the Authentic Community). This name implies their self-perception of being part of an international majority movement within Sunni Islam grounded within the ongoing tradition. They permit praiseworthy innovations within Islam, following the majority position, provided that they are in keeping with the Qur'an and Sunna. They embrace Sufi etiquette and practice, are the traditional custodians of the shrines of the Friends of God (*awliya*) in the Subcontinent, and have developed an understanding of the intercession, both of Muhammad and the *awliya*.

**Bebay:** Mother

Beli	Comrade/old acquaintance/trustworthy/confidant
Biraderi:	Brethren, Brotherhood
Bistra	Bed, bedding
Boosky	Boosky is an off-white, silk fabric
Buddha	Shakyamuni Buddha (Siddhartha Gautama) was born as a prince. Siddhartha abandoned his regal life and began a lifelong search for religious insight. After a period of intense meditation, he arrived at the core beliefs and practices of Buddhism, and established a community of followers and disciples, who were responsible for propagating his teachings after his death.
Chaudhry	The surname 'Chaudhry' refers to a person with influence and powerful. So an influential person in a village is called as 'Chaudhry'. The basis of being influential is the possession of land, hailing from a martial race of the Punjab. A Chaudhry is supposed to be well versed in politics, running a men's room, and resourceful by being known in police and district administration, among the judiciary and politicians of all levels. It is basically his support structure that makes him influential and in bargaining position.
Chehlum	The fortieth immediate day after the death of a person in the Islamic tradition. On the fortieth day, the Maulvi is presented with valuable articles of the deceased along with food and fruits.
Cholistan	The Cholistan is a desert covering an area of 26,000 Km <sup>2</sup> located between 27°42' and 29°45' N latitude and 69°52' and 75°24' E longitude at a height of 112 m above sea level. Its old civilization has vanished mainly due to a variety of hostile invading problems



caused by the Egyptian, Harappan and Mesopotamian civilizations. The prominent climatic features of the Cholistan desert are sub-tropical, arid, burning hot, monsoon rainfall with intermittent long droughts and strong summer winds having relatively low humidity and high rate of evaporation. The desert is separated into two eco-regions by old Hakra River. The northern division covers about 7,770 km<sup>2</sup> and is known as Lesser Cholistan. The purely aeolian sandy desert, called the Greater Cholistan covers 8,130 Km<sup>2</sup> in the southern region consisting of various forms of sand ridges and inter-ridges valleys. It extends about 480 km in length and 32 to 192 km in width.

Deobandi

The answer of the founders of the Deobandi Movement, Muhammad Qasim Nanutavi and Rashid Ahmad Gangohi, lay in education. They founded a centre of Islamic Studies in the town of Deoband in Saharanpur District. From this base, they established a chain of madrasas (schools) throughout India and wherever their followers migrated around the world. The principles that underlay this movement were a turn to the purity of the Qur'an and Hadith as the two main principle sources of Islam, and an avoidance of elements associated with Hindus or British values. They emphasized the importance of the Hanafi School of Sunni Shari'a, and avoided anything that might be drawn from Shi'a practices. A restricted form of sufi practice was permitted, but there was to be no intercession of pirs.

Desi ghee

Boiled butter; the universal medium of cookery throughout South Asia. In general, ghee is prepared by four methods, namely, desi, creamery butter, direct cream and pre-stratification methods. The desi method consists of churning curdled whole milk (dahi) with

an indigenous corrugated wooden beater, separating the butter, and clarifying it into ghee by direct open pan heating.

Dhaba	Dhabas (as plural for Dhaba) are small local restaurants and or also truck shops which are usually located along the highways. Dhabas generally serve delicious, heavily spiced dishes preferred by many travellers. The standard drink is chai.
Dhian	Daughters
Dhoti	A traditional dress locally worn by peasants, farmers, and also a few landlords in the villages of Pakistan, specifically the Punjab. It is an unstitched piece of cloth, tied around the waistline.
Dobari	Rotatory crop; for example sunflower is being raised on residual soil moisture in rotation with rice as a dobari crop.
Eid Milad	12 Rabi' al-awwal is the accepted date among most of the Sunni scholars, while Shi'a scholars regard 17 Rabi' al-awwal as the accepted date. Muslims celebrate Eid Milad-un-Nabi, the anniversary of the birth of the Prophet Muhammad, because he is their beloved Prophet, the recipient of the Holy Quran. The extent of the festivities of this day is restricted, since it also marks the anniversary of the Prophet's death. Prayers are offered in mosques, and scholars recount events that emphasize the Prophet's noble character. Songs are recited in his praise, as well as poetic verses from the Quran. Charitable donations are made freely and generously. Friends get together to have sumptuous meals, and food is served to the poor, and also distributed amongst guests visiting the shrines.
Eid-al-Azha	Also known and pronounced as Eid al-Adha ("Festival of Sacrifice") is the second of the two great Muslim festivals, the

other being Eid al-Fitr. Eid al-Adha marks the culmination of the hajj (pilgrimage) rites at Minā, Saudi Arabia, near Mecca, but is celebrated by Muslims throughout the world. It begins on the 10th of Dhu'l-Hijja, the last month of the Islamic calendar, and continues for an additional three days. During the festival, families that can afford to sacrifice a ritually acceptable animal (sheep, goat, camel, or cow) do so, and then divide the flesh equally among themselves, the poor, and friends and neighbours. Eid al-Adha is also a time for visiting with friends and family and for exchanging gifts. This festival commemorates the ransom with a ram of the biblical patriarch, Ibrahim's son Ismail, rather than Isaac, in Judeo-Christian tradition.

Eid-al-Fitr

It is the first of two canonical festivals of Islam. Eid al-Fitr marks the end of Ramadan, the Muslim holy month of fasting, and is celebrated during the first three days of Shawwal, the 10th month of the Islamic calendar. There is a performance of the communal prayer (ṣalāt) at daybreak on its first day. Eid al-Fitr is a time of official receptions and private visits, when friends greet one another, presents are given, new clothes are worn, and the graves of relatives are visited.

Fajar

The first prayer of the day is at dawn before sunrise comprising of two units.

Gandhara

The region along the northern boundaries of the huge, culturally and ethnically diverse South Asian sub-continent was known in ancient times as Gandhara. It remained isolated until the beginning of 6th Century BCE, not only from the other regions of the South Asia, but also from the region beyond its northern boundaries. Around 535 BCE, the massive wall formed by the Hindu Kush and the Kara Koram mountain ranges was ultimately breached by the

Persian armies under Cyrus the Great. In 438 BCE, Darius the Great extended the Persian possessions in South Asia by conquering the Taxila region east of the Indus.

- Ghuman                      The Ghuman are of both Rajput and Jat status in Pakistan. The Ghuman claim descent from the Janjua. They are found primarily in Sialkot and Gujranwala districts
- Guddi Gudda                This is one of the popular games of girls. Pieces of cloth are used for making dolls. Toy kitchen goods made of plastic or tin are bought at the market. Toys made up of clay, cloth or wood are sold during festive periods. Sometimes they arrange marriage for dolls. At first, they divide themselves into groups. One group acts as the boy's party, and the other group acts as the girl's party. They sing and dance, and perform all the rituals of a real marriage.
- Gulli Danda                A locally played sport, mostly in the rural areas of Pakistan. It consists of two sticks, longer one being the Danda, while the shorter one being Gulli. The name stems from the two sticks that are the only real equipment. The gulli is about five inches long, and the danda is about two feet long. Both are cut from the same length of wood and should be about an inch in diameter. The shorter gulli is then sharpened to a dull point at each end, while the danda is pointed at only one end. The game is played in an open field and can be played by two equal-numbered teams (normally not to exceed seven per team) or two individuals. It is played in India, Pakistan, and Sri Lanka, with only slight variations, and also goes by the names of gilli danda or danda guli in the two former countries, while known primarily as gudu in Sri Lanka.
- Hakeem                      A physician using traditional remedies in India and Muslim countries. Hakeem is literally from Hikmat which means wisdom.

Haveli	It is a traditional townhouse or mansion in India, Pakistan, Nepal and Bangladesh, usually one with historical and architectural significance. The word haveli is derived from Arabic hawali, meaning "partition" or "private space" popularized under Mughal Empire and was devoid of any architectural affiliations.
Hindu Fakeer	Also known as <i>fakir</i> , meaning 'poor'. Properly an indigent person, but specially 'one poor in the sight of God,' applied to a Mahomedan religious mendicant, and then loosely, to Hindu devotees and naked ascetics.
Imam	Prayer leader, Mosque leader, Spiritual leader
Imam-bargah	Also known as 'Imam-baara', it is a hybrid word <i>Imām - bārā</i> , in which the last part is the Hindī <i>bārā</i> , 'an enclosure'. It is applied to a building maintained by Shī'a communities in India, for the expression and celebration of their religious ceremonies and rituals e.g. majalis and milads.
Jalebi	A rich sweetmeat made of sugar and ghee, with a little flour, melted and trickled into a pan, so as to form a kind of interlaced work, when baked.
Jaloos	Religious procession enacted during holy months in Islamic calendar including Muharram and Rabi al-awwal.
Jhalay Shah	The name of the Muslim saint who lived his life in simplicity.
Kameez	A long top with a pair of loose trousers, traditionally worn in the Sub-continent. It is also the national dress of Pakistan, mostly common in the Punjab.

Kammi	It literally means a worker, but in Punjab's socio-historical context the word has wider connotations. It's a generic term applied to all the traditional producers of specific goods and community service providers without which we could not conceive our social and cultural life till recent times. The word 'Kammi' gradually came to be associated with the artisans and artists who were considered to be of low caste or low status in a hierarchy-ridden society which looked at work with disdain. (Soofi, 2014)
Kasai	Butcher
Katba	Epitaph
Katcha	Unpaved, made up of mud or clay bricks
Khandan:	Extended family, clan, from the related brethren
Kharif	Kharif crops or monsoon crops are domesticated plants that are cultivated and harvested in Punjab.
Khatai	Also known as Nankhatai are shortbread biscuits popular in India and Pakistan. The word Nankhatai is derived from Persian word Naan meaning bread and "Khatai" from an Afghan word meaning Biscuit.
Kunba:	Clan
Langar	It is the charitable distribution of eatables and community meal, mainly at the Sufi shrines, organized for the poor and the visitors. It is also distributed on important Islamic days and during the mourning days in Muharram.
Latha	A white, cotton fabric

Maa	Mother
Maghrib	The fourth prayer comprising of three units, which is offered immediately after the sunset, in the twilight. The fourth prayer is offered in three units soon after the sunset when the day has folded successfully. It is time to express gratitude to Allah for a well ended day and seek his forgiveness for all sins.
Mahavira	Lord Mahavir was the twenty-fourth and last Tirthankara of the Jain religion of this era. Lord Mahavir was born in 599 B.C. in the state of Bihar, India. Mahavir was a prince and was given the name Vardhaman by his parents.
Makran	Makran extends along the northern shores of the Arabian Sea between Karachi and the Persian Gulf, commencing from the Sonmiani bay on the east, and terminating somewhat indefinitely on the west within the recognized territory of Persia. Makran is a geographical rather than a political territorial designation, and may be called the most southern district of South-Western Baluchistan. The Makran coast has featured in the archaeological and historical records from at least as early as the third millennium B.C.
Mangni	Engagement
Manjian	Plural for Manji (is a traditional woven bed)
Mehrgarh	Mehrgarh is the site in the Kachi district, Baluchistan in Pakistan. It lies at the foot of Bolan Pass, and very much incorporated in the Indus System. The Neolithic site spans over an area of nearly 500 acres with remains only of the pre-Harappan times. Mehrgarh as a pre-Harappan site is of utmost significance in the history of the subcontinent. Mehrgarh has been in the course of excavation for

the past decade by the French Archaeological Mission led by J.F. Jarrige.

- Mirasi                      The term Mirasi derives from miras, simply meaning lineage. (Saeed, 2001) They are bards, impersonators, genealogists, singers, dancers and storytellers like the Bhat in the Punjab, Pakistan and northwest India. The Mirasi specialize as bhand, or comedians. Teams of Mirasi musicians and singers perform songs of romantic love. A Mirasi is a sort of low-class minstrel whose women dance and sing, but only it is said in the shelter of the zenana, and in the presence of the other women. The Mirasi attends weddings and funerals, where he recites the genealogies of the wedding pair or describe the brave acts of the dead man's ancestors.
- MohenjoDaro              It is an archaeological site in the province of Sindh, Pakistan. Built around 2500 BCE, it was one of the largest settlements of the ancient Indus Valley civilization, and one of the world's earliest major cities, contemporaneous with the civilizations of ancient Egypt, Mesopotamia, Minoan Crete, and Norte Chico. Mohenjo-daro was abandoned in the 19th century BCE as the Indus Valley Civilization declined, and the site was not rediscovered until the 1920s. Significant excavation has since been conducted at the site of the city, which was designated an UNESCO World Heritage Site in 1980. The site is currently threatened by erosion and improper restoration.
- Mooray                      Plural for Moora (is a traditional stool mostly made up of cane)
- Muḥarram                      It is the first month of the Islamic calendar. It is one of the four sacred months of the year. It is held to be the holiest month, Ramadan coming after. The word "Muharram" means "forbidden".



Since the Islamic calendar is a lunar calendar, Muharram moves from year to year when compared with the Gregorian calendar.

Mushaf Base	It is a Pakistan Air Force airbase located at Sargodha in the Punjab province of Pakistan. It is the headquarters of the PAF Central Air Command. It was known as PAF Base Sargodha until 2003, when it was renamed in honor of former Base Commander and Chief of the Air Staff Air Chief Marshal Mushaf Ali Mir, whose airplane crashed on a routine flight near Kohat the same year.
Muza'ray	Tenants and Sharecroppers; Muzara (Singular) Muza'ray (Plural)
Naan	Bread, also baked bread baked in cylindrical oven (known as tandoor).
Nahoosat	Unholy, evil, bad omen
Nai	Barber, also offer services as caterer
Namak-para	Namak-para is a salty ribbon-like strip of pastry, delicately seasoned with ajwain, cumin seeds, carom seeds, and caraway seeds and deep fried in pure ghee.
Nauwan	The ninth immediate day after the death of a person in Islamic tradition. The day themes recitation of the Holy Quran, and other prayers, for the absolution of their sins. The guests (extended family and relatives) from the far flung areas usually leave (to their respective towns) after the Nauwan or immediately next morning.
Nazim	Nazim refers to 'an organizer' on the cities and town level of Pakistan. It is an official post for the local or decentralized government. Each level of local government has elected councils,

nazims (mayors), and naib (deputy) nazims. A nazim and naib nazim are directly elected to the union council on a joint ticket.

Niaz	Blessed food distributed among the devotees in religious ceremonies and rituals.
Nikah	A formal, Islamic bond between a man and a woman
Nikah Nama	Marriage contract
Paeo	Father
Paika	Paternal family (especially used for married daughters)
Pakka	Paved, Cemented, made with bricks
Pakora	Pakora, also known as a fritter, is a savoury deep-fried cake, containing bits of cauliflower, eggplant, or other vegetables.
Paneeri	Paneeri is a traditional form of cheese seasoned with dry nuts, which is produced from sour milk. Paneer is marble white in appearance, having firm, cohesive and spongy body with a close-knit texture and a sweetish-acidic-nutty flavour.
Paroonachari	Guest welcoming
Peshawari Chappal	Peshawari Chappal is a type of sandal, made from a separate insole, sole and heel, two vamps, two quarters and one back strap, and is fitted with buckles for fastening.
Piri	A four legged stool (used for seat) traditionally woven.
Putar	It literally means ‘Son’; also considered as heir

Qaum	Caste is the purest type of social stratification in which mobility is severely constrained. The term Caste has been commonly used to describe any system in which the different strata are rigidly fixed. In the Indian case, strata are divided not by physical distinctions between groups but by people's social descent.
Rabi	Rabi crops or Rabi harvest are agricultural crops sown in winter and harvested in the spring
Ramadan	It is the ninth month of the Islamic Calendar, in which the Muslims are obligated to observe fasts throughout the month. The month of Ramadan also marks the dates of Shab-e-Qadr, or the Night of Value, during the last ten days. Ramadan, the ninth month of the Islamic lunar calendar, is a holy time in the Muslim world. For all observant Muslims it is a full month of fasting in commemoration of the first verses of the Qur'an being passed down from heaven to the Prophet Muhammad. The Qur'an quite plainly states the historical, spiritual and didactic reasons for requiring the fast in verses 2:183-5. 'O you who believe! Fasting is prescribed to you as it was to those before you, that you may learn self-restraint. Ramadan is the (month) in which was sent down the Qur'an, so every one of you who is present (at his home) during that month should spend it in fasting.'
Sahelian	Female friends; childhood female friends
Sajan	Close friend/Soul mate
Salana	Yearly; death anniversary or a year after the death of a person. Every year on the death anniversary, prayers are offered by the Maulvi in commemoration of the dead. A few perform barasee

(death anniversary) within the household by performing fateha (opening surah of Quran) ceremony.

Saura

Also known as Sauray which means in-laws

Shatapoo

Shatapoo is a game where you throw a stone at a number and hop to the box where the stone lands, and is like hopscotch. A rectangle about three yards long and two yards wide is drawn. This rectangle is divided into six squares each about a foot wide. The first player stands before the starting line and tosses the stone into the first square, picks the stone and hops onwards without stepping over the box on which the stone has been tossed, and then hops back. This process is repeated for the subsequent steps. The player is declared out if the stone fails to land in the appropriate square, or the player steps on a line, or loses her balance while bending to pick up the stone, or puts her other hand or foot down, or steps into the square in which the stone has been tossed.

Shia

The sect was born as a political faction, soon after the death of Islam's founder, Prophet Muhammed. According to the Shi'a, the "party (shi'a) of Ali", Muhammad was on the way to Madina when at the pond of Khumm, he appointed Ali to be his successor. As the Shi'i later taught, the blood descendants of Muhammad inherited his prophetic charisma, and thus, were currently called upon to lead the community. The Twelver Shi'as are by far the largest Shi'a sect. The name 'Twelver' refers to the series of twelve leaders (Imams) from the family of Prophet Muhammad, who according to the beliefs of adherents of this domination were appointed by God.

Sillanwali

The town developed in the late 19th century during the rule of the British empire. It was planned to be an agricultural business hub or

mandi ("wholesale market"). It was a planned town developed after canals were built for agricultural purposes and a railway line was established. Even today, the railway station at Sillanwali is known as "Sillanwali Mandi" in railway records. Before the Partition of India in 1947, Sillanwali was well known for the production of cotton. Most of the population were Hindu Khatri. After partition the Hindus migrated to India and their property was taken over by the Muslim Sheikhs (having Khatri Origin), most of whom had migrated from Karnal District of Haryana state which had been part of united Punjab but became part of Indian Punjab after 1947.

Soyam

The third immediate day after the death of a person in Islamic tradition. The relatives of the deceased recite the Holy Quran, so that blessings may descend upon the departed soul and their sins cascade down. Up till third day after death no food is cooked in the house of the deceased. On the third day Ziyarat, special prayers are offered by the Maulvi (prayer leader) for the peace of the departed soul and a special preparation made of clarified butter, rice and wheat flour, and is distributed among the children and attendants.

Sunni

A Sunni is a person who strives to live and act according to customs and traditions. The substance of the customs consists of the sayings and teachings that were passed down from Prophet Muhammad (PBUH). The sect was born as a political faction, soon after the death of Islam's founder, Prophet Muhammed (PBUH). The Sunnis believed in choosing Mohammed's successor through the consensus of the majority of believers. The Sunni majority spoke out for the selection of the caliph from the Quraysh tribe, the Meccan 'nobility'. Abu Bakr emerged as a victor from the rivalries that broke out after Muhammad's death. The Sunnis founded the

Khilafa (Caliphate) which changed hands many times and ended only in 1924 with the fall of Turkish Ottoman Empire.

Tabbar Family

Taxila The remains of Taxila are situated immediately to the east and north-east of Sarai-kala, a junction on the railway, twenty miles north-west of Rawalpindi. The valley in which they lie is well-watered by the Haro River and its tributaries, and protected by a griddle of hills-on the north and east by the snow mountains of Hazara and the Murree ridge, on the south and west by the well-known Margalla spur and other lower eminences. Arrian speaks of it as being a great and flourishing city in the time of Alexander the Great, of all the cities which lay between the Indus and the Hydaspes (Jehlam).

Visakh Mela Wheat harvesting festival

Waris Heir, also the potential owner, custodian and care taker of the property (land).

Yaar Companion/friend

## **Chapter Five**

Baji Sister, mostly an elder sister

Bazoori The chief ingredient of Sharbat Bazoori is Beikh Kasni (Cichorium intybus root). Kasni roots are known as Chicory in English. It is a Sharbat of seeds. Bazer means seed and its plural is Bazoor (seeds). Because seeds are included in this formulation particularly, it is called Bazoori. Sharbat or Syrup means the sweet

syrup compound, prepared from decoction, infusion, and water extract of either dry fruits or herbs or seeds etc.

Bhabhi	Brother's spouse/wife in traditional language.
Booti	Herbs, shrubs, plants used for cooking and medicinal purposes in the indigenous culture of Pakistan, such as mint or podina, coriander or hara dhaniya, which are also used for relieving stomach aches and other related issues.
Buzurgo	Literally means elderly, fatherly, respected
Chacha	Father's brother, here it means fatherly, elderly, respected
Chapati	It is an unleavened flatbread
Chiniot	It is a city and the administrative headquarter of Chiniot District in the state of Punjab, Pakistan. On the bank of the river Chenab, it is known for its intricate wooden furniture, architecture, havelian, and mosques.
Chopri Roti	Chopri Roti is an indigenous food, which is made by applying butter, or ghee on a traditional, wheat Roti, Chapati, or flatbread. The Roti is made by kneading wheat dough with water, and then rolled to make a round shape. After the Roti is cooked, butter or ghee is applied while it is still hot.
Chutney	It is a traditional, complimentary sauce often tasted with daily meals in Punjab.
Daig	A big, round pot, made up of steel, used for cooking purposes in Pakistani culture, mostly for larger gatherings or occasions such as marriages, religious processions.

Dam	It is to recite (silently and explicitly) the holy words from the divine scriptures and blow it on the patients or devotees.
Din	Day, Day light
Doodh	Fresh milk; a white, smooth, natural drink which, in the Pakistani culture, is mostly taken from cows and goats.
Ghar	Home, House
Goli	Tablet, also used for medicine
GT road	Grand Trunk Road
Gurh	It is a concentrated product of date, cane juice, or palm sap (see palm sugar) without separation of the molasses and crystals, and can vary from golden brown to dark brown in colour.
Habas	Humidity
Handi	A cooking utensil in traditional Pakistani culture, made up of metal or clay. Handi is also known as food (that is prepared daily in the form of gravy or rice dishes).
Hikmat	Wisdom, a traditional for of knowledge carried chest by chest in the community specific to environment and ecology.
Hookah	It is a single- or multi-stemmed instrument for vaporizing and smoking tobacco, whose vapor or smoke is passed through a water basin often glass based before inhalation.
I'tikaf	It is a practice of staying in the mosque and performing extra deeds of devotions in the absence of public scrutiny.
Ibadah	Prayers



Iftari	It is a post-sunset meal in the Muslim traditions, in the month of Ramadan, which marks the termination of the fast. The most common fruit eaten in Iftar are dates. Iftari mostly constitutes meals, such as halwa puri, kachori, fruit-chart, and beverages such as milkshakes, lemonade, and Sharbat.
Isha	The fifth and final prayer, offered when the night darkens.
Jam e Shireen	Jam e Shireen means ‘a sweet goblet’. Jam e Shireen, like RoohAfza, is also a local, herbal beverage which is usually drunk in the summers, to have a sweep of refreshment. Jam e Shireen can be prepared with both water and milk, and includes rose, sandalwood, and other herbs to give it a hint of vitality.
Jhang	It is the capital city of Jhang District, in the province of Punjab, Pakistan. It is situated on the east bank of the Chenab river.
Kabaddi	It is a traditional sport, mostly played in the rural areas of Pakistan especially Punjab. It is a game that would be remarkably easy to adapt to any schoolyard, since there is virtually no equipment required.
Kala jadoo	Black Magic
Kalla	Alone, to feel all alone
Kamzoor	Weak, weakness
Karela	Bitter ground
Katchi-lassi	Milky water, a small quantity of milk is added in a jug of water and is considered to fight the heat of the summers (especially in Punjab).

Khali	Empty, feeling empty
Khana	Food
Kheer	A thick rice or vermicelli pudding made from boiled-down milk (khoya). Kheer is a traditional sweet-dish of Pakistan, mostly served after meals or on festive occasions such as marriages, religious occasions like Eid-ul-fitr and Eid-ul-Adha. It is white in color, has a soft and smooth texture, and often garnished with nuts.
Lassi:	A local, indigenous drink made from adding yoghurt to milk. It can be both sweet and sour, depending upon the quantity of sugar added. Lassi is a summer drink, with a frothy texture. But the form in which it is most cherished and unbeatably popular in probably the homes of all the millions who constitute the Punjab is called lassi: the sweet or salty summer yoghurt drink that is traditionally served to cool people down as they enter a home to escape the burning blistering sun in rural Punjab.
Maan	Mother, Motherly
Malai	Cream, Milkfat
Meetha	Sweet, sugary
Missi	Salty
Miswak	A tooth-stick; a traditional, indigenous tool to clean teeth, mostly by the Muslims on the recommendation of the Prophet Muhammad (PBUH). Miswak ( <i>Salvadora persica</i> ) is one of the oldest known shrubs, being used by millions of people in various parts of the world as an oral hygiene tool.

Mithai	Mithai is from Meetha which means sweet, and are traditional sweets.
Murabba	Preserve; is a traditional ‘preserve’ of fruits and vegetables in traditional societies of Pakistan, such as Mango Preserve or Aam da Murabba, Carrot Preserve or Gajjar da Murabba. It is prepared by adding boiled pieces of fruits to sugar syrup, with a tinge of citric acid. Murabba, along with the significance of preserving fruits, it is traditionally considered to also have health benefits.
Nashta	Breakfast
Nazar lagna	Evil eye
Niqab	It is to cover the face; veil
Pehlwani	It is also known as kushti or traditional form of wrestling. Pehlwani is a traditional, folk-sport which is practiced in the rural societies of Pakistan.
Purdah	The custom, found in some Muslim and Hindu cultures, of keeping women from being seen by men they are not related to, by having them live in a separate part of the house or behind a curtain, and having them wear clothing that covers the whole body, including the face.
Raat	Night
Rooh afza	Rooh Afza means ‘nourishment of the soul’. Rooh Afza is a local beverage since the Sub-Continent, which is domestically used to relieve the heat of the hot summer days.
Sandal Sharbat	Sandalwood Syrup. It has benefits for cooling down of body, kidney and liver-related problems. It is prepared by boiling

sandalwood in water, and then cooking with sugar syrup. It is considered to calm the heat of the heart, body and helpful to control head spinning in summers.

Sehri	It is the meal, or breakfast, which is made before the sunrise, and the morning prayers in the Muslim tradition, particularly in the month of Ramadan. Most common Sehri meals include some indigenous foods such as yoghurt, parathay, lassi.
Shakar Sharbat	Shakar is raw, brown sugar in traditional Pakistani language. Shakar da Sharbat is a local indigenous, summer beverage or syrup, prepared by mixing raw, brown sugar in cold water.
Sharbat	It is a local beverage in Pakistan's culture, usually made on festive occasions, or in summers to have a taste of chilled drink on a hot day. It is usually sweet, prepared from the combination of the essence or extract of a flower or a plant with sugar, and artificial food colours in some cases. Sherbet can be a medicinal drink, a syrup or juice concentrated to a certain degree of viscosity. Sugar or honey is usually added to it in order to thicken and sweeten it.
Tablighi Jama'at	A group of people who preach their own set of religious beliefs and principles. The bulk of academics and other observers see Tablighi Jamaat as peaceful, apolitical, and law-abiding
Thinda	Oily, food cooked in ghee or desi ghee
Totkay	Plural for Totka is an indigenous recipe or medicine to alleviate or soothe an affliction, traditionally.
Wada	Head of the house; used in a specific context when one takes position/status in the family after the death of a father (previously head of the house).

Zarda

A kind of pulao made from rice, raisins, sugar, nuts, and saffron. It is a yellowish, traditional dessert, mostly prepared on festivities in Pakistan. It can optionally be garnished with dried-fruits and sweets. Zarda is prepared by cooking rice in sugar syrup, and food colour is added to give it a yellow colouring.

## **Annexure**

# Desk Guide



**MANAGEMENT** of  
**Hypertension-CVD**  
& **Type-2 Diabetes**  
Primary Health Care in Pakistan

## Identify and respond to a severe condition

**Assess for a severe condition – on the basis of following complaints and vital sign abnormality.**

### Complaints

- Chest pain > half hour at rest (MI);
- Chest pain with few minutes exercise, going away at rest (angina)
- Shortness of breath and ankle swelling (heart failure)
- Sudden one-sided weakness/ slurred speech/ vision loss (stroke/TIA)
- Pain in the back of lower legs or buttocks on walking, relieved with rest (peripheral vascular disease)
- Altered consciousness (blood glucose: < 70mg/dl or > 360mg/dl, or volume depletion)
- Severe numbness hand and feet (neuropathy)
- Leg ulcer/ gangrene or infection (fever > 98.6° F)

### Vital sign abnormality

- Pulse: > 120/ minute and patient feel fainting
- High Systolic BP\*: > 200 mm of Hg (with or without signs of CVD)
- Low Systolic BP'': < 90 mm of Hg (with signs of shock)
- Respiratory rate: > 20/ minute (shortness of breath)

**If severe** condition, stabilize the patient, and then refer to the hospital (see CMG page 11 and 12)

**If no severe** condition, assess for the diagnosis of hypertension and/or diabetes.

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\* OR High Diastolic BP: > 110 mm of Hg (with or without signs of CVD)

''OR Low Diastolic BP: < 60 mm of Hg (with signs of shock)

## Diagnose Hypertension and Type-2 Diabetes in Adults

⇒ Investigate for hypertension and/or type-2 diabetes, if adult **patient**:

- Appears to be overweight\* (i.e. more than target weight in Appendix-3), OR
- Has family history of hypertension and/or type-2 diabetes, OR
- Presents with one or more of the following complaints:

Hypertension	Type-2 diabetes
Dull headaches, light headedness	Increased thirst and/or hunger and/or frequent urination
Nose bleed	Recurrent infections, thrush, skin boils
Type-2 diabetes	'Pins and needles' in feet
Feeling tired or difficult to concentrate	
Blurred vision	

### Hypertension

Take two consecutive readings, one minute apart, and record the lower reading as the clinic blood pressure<sup>#</sup>. If the clinical blood pressure is:

- More than 140/90 mm Hg, label and manage as hypertension.
- Less than 140/90 mm Hg, life style counsel and reassess after month 1 and 6.

### Type-2 Diabetes:

⇒ Check random blood glucose, RBG (mg/dl), If RBG is:

- Less than 140 mg/dL, then no further assessment.
- 140 mg/dL or more, then next morning

⇒ Check fasting blood glucose (FBG), if FBG is:

- 110 – 125 mg/dL, then repeat FBG testing after 1 month.
- 126 mg/dL or more, then label as diabetes, register and treat.

#### Note hypertension:

- Make sure patient has not carried out any physical activity (e.g. walking) in the last five minutes.
- If difference in the two consecutive readings is > 5 mm Hg, then take a third measurement and record lower of the last two measurements as clinic BP.
- Do not record BP when patient is under stress, has consumed tea/ coffee, smoked tobacco or done exercise in the past 30 minutes



## Conduct Baseline Clinical Assessment

Each diagnosed case is weighed and assessed for a set of associated conditions and special conditions (e.g. pregnancy) as follows:

### Associated Conditions:

A patient diagnosed with hypertension must undergo assessment for diabetes and vice versa.

- ⇒ Assess for **heart attack or heart failure or other CVD** in the past (e.g. stroke, transient ischemic attack, angina, claudication) by asking & checking records
- ⇒ Assess for **Renal function** by examining for ankle edema and peri-orbital puffiness, and checking proteinuria on two occasions (at least 6 hour apart)
- ⇒ Assess for **hypercholesterolemia** (i.e.  $\geq 200$  mg/ dL) by checking blood cholesterol

### Special and Other Conditions:

- ⇒ Assess for **smoking status** by asking patient, and if smoker then suggest stop smoking, and if patient agrees then refer for smoking cessation counseling
- ⇒ Assess for **eye complaints** (i.e. effects of HTN and/or diabetes) by asking patient, and if yes - refer for eye specialist opinion.
- ⇒ Assess for **pregnancy** by asking for late/uncertain LMP and testing urine, if pregnant assess the risk of preeclampsia<sup>#</sup>, if positive then refer to hospital (# Note on signs: sudden weight gain, face & hand edema, and proteinuria)

### Inform patient about (by the physician):

- Disease: hypertension and/or type-2 diabetes, require lifelong management
- Effective disease management: affects the longevity and the quality of life.
- Effective disease management includes regular drug intake and healthy lifestyle i.e. diet, exercise, weight control and no-smoking.
- Report to the doctor if any “unusual” symptom/complaint is noticed.
- Guide/refer to the designated paramedic for structured counselling session

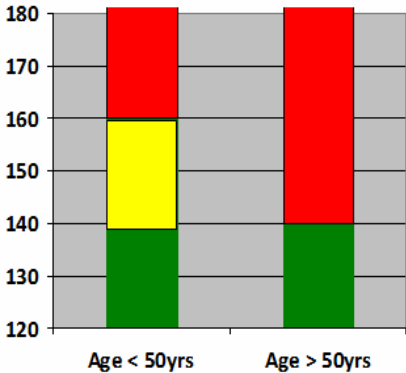
## Treat for Hypertension and Type-2 Diabetes

⇒ Offer **life style counseling** to every person with hypertension or/and diabetes, which includes diet, exercise and smoking cessation (use the communication tools i.e. flip book and brochure).

⇒ **Guiding Principles** (for treatment of hypertension and diabetes)

- Prescribe anti hypertensive and/or anti-diabetic drugs after diagnosis
- Start the treatment with the lower recommended dose
- Change the dose or add drug only after four weeks of anti-hypertensive and eight weeks of anti-diabetic drug intake,
- Increase dose of a drug up to the upper limit of maintenance dose (if inadequate response).
- Add a new drug if upper limit of the maintenance gives inadequate response

⇒ Assess risk initiate anti-treatment as



and decide to hypertensive follows:

**Key:**

- : Life style counseling only
- : Add anti-HTN regimen, only if associated condition<sup>#</sup>.
- : Add anti-HTN regimen, regardless of associated condition<sup>#</sup>.

**#: Associated conditions (for anti-HTN regimen SBP: 140 - 159)**

Diabetes	Smoking	Serum cholesterol
Yes	Yes	≥240mg/dL
Any one of the two is yes		≥320mg/dL
Renal compromise regardless of diabetes, smoking, serum cholesterol level.		

Based on risk ≥ 20 - WHO/ISH "CVD Risk Prediction Charts EMRO"

## Treat Hypertension

### Hypertension without an associated condition

**Start with step-1, and go to the next step if BP remains 160 mm Hg or more (or DBP remains 100 mm Hg or more).**

Step-1:

⇒ Thiazide

Step-2:

⇒ Add ACE inhibitors or CCB

Step-3:

⇒ Thiazide plus ACEi plus CCB

Step-4:

⇒ Label as resistant hypertension, and refer.

### Administer preventive treatment<sup>1</sup> (in hypertension/diabetes)

Diabetes	SBP (baseline)	Smoker	Serum cholesterol
Yes	SBP: ≥140 or smoker or serum cholesterol ≥ 200mg/dL		
No	≥180		
	160 – 179	Yes	≥ 240mg/dL
		No	≥ 320mg/dL
Renal compromise regardless of diabetes, smoking and/or serum cholesterol levels.			

(Note: Shaded cell means "not relevant" for decision to administer preventive therapy)

### Administer

👉 Simvastatin 10 mg OD (at night), then add 10 mg /day if inadequate response in 8 weeks. Increase the dose up to 40 mg / day.

(caution: exclude pregnancy, breast feeding & active liver disease)

<sup>1</sup> Mainly based on risk ≥ 30 - WHO/ISH "CVD Risk Prediction Charts EMR D"

- 👉 Aspirin (enteric coated) 75 mg daily (after meal)  
(caution: exclude pregnancy, breast feeding, bleeding tendencies & dyspepsia)

- if ACEi causes dry cough, replace with ARB
- exclude MI/ HF/other CVD for prescribing CCB

## Treat Hypertension

The treatment of hypertension with associated conditions covers only the hypertension regimen, whereas the treatment required for the associated diabetes is covered in the next section of the guide (Note: The prescription for other associated conditions is not covered).

**Start with step-1, and go to the next step if SBP remains 160 mm Hg or more (or DBP remains 100 mm Hg or more).**

### **MI / HF / Other CVD:**

⇒ Refer to the specialist, if history of MI / HF / other CVD.

### **Diabetes and/or Renal insufficiency**

- ⇒ If baseline proteinuria is 4+, then refer for nephrology consultation
- ⇒ If baseline proteinuria is 1+ to 3+, treat for hypertension as follows:

#### Step-1:

- ⇒ ACE inhibitors or ARB  
(caution: withhold treatment and refer, if signs of hyperkalemia i.e. palpitations and muscle weakness { $K^+ >5$  mEq/ L})

#### Step-2:

- ⇒ Add Thiazide or loop diuretics (if no worsening proteinuria, or hyperkalemia)

#### Step-3:

- ⇒ Label as resistant hypertension, and refer.

### **Pregnancy** (without signs of preeclampsia)

#### Step-1:

- ⇒ Methyldopa  
If not tolerated then change, or systolic BP remains 160/100mm Hg or more,

#### Step 2:

- ⇒ Add hydralazine (oral)

During the breast feeding period:

⇒ Manage with ACEi and/or CCB, also add a beta blocker, if needed.

**Caution:** ACE inhibitors and ARB are contraindicated in pregnancy.  
Thiazide & methylodopa not recommended during the breast feeding period

**Prescribe anti-hypertensive drugs**

Drug			Daily dose (mg)				Comment
Class	Name	Tablet	Initial	Add <sup>#</sup>	Maint.	Max.	
<b>Anti-hypertensive drugs</b>							
CCB	Amlodipine-besylate	5 mg 10 mg	5	2.5	5 -10	10	O.D <sup>2</sup> Cl: MI/HF
ACE inhibitor	Enalapril	5mg 10mg 20mg	5	5	10 – 20	40	O.D or B.D
Thiazide Diuretics	Hydro-chlorthiazide	25mg	12.5	12.5	12.5 – 25	50	O.D or B.D
Beta blockers	Atenolol	25mg 50mg 100mg	50	25	50 -100	100	O.D
Centrally acting drugs	Methylodopa	250mg	250	250	250-2000	3000	B.D or TiD
Vasodilator	hydralazine	25mg	25	25	25-100	100	B.D
<b>Cholesterol lowering drugs (both in hypertension and diabetes)</b>							
Statins	Simvastatin	10mg 20mg 40mg	10	10	10-40	40	O.D at nights
<b>CVD prevention drugs (both in hypertension and diabetes)</b>							
Anti platelet agent	Aspirin	75mg 150mg 300mg	75	75	75-150	150	O.D Cl: H/o bleed tendency, liver disease, age < 21

<sup>2</sup> Cl: contraindicated, MI: myocardial infarction, HF: Heart failure

							or >80 yr.
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(# mgs to be added or reduced from the current daily dose)

key: O.D = once daily, B.D= twice daily, T.i.D= thrice daily, q.i.d= four times a day

For other anti-hypertensive agents, not included in the essential drug list, please see Appendix-1.

## Treat Type-2 Diabetes

### Decide to Treat

⇒ If FBG 126 – 199 with no associated condition

👉 Start life style modification, add drugs if inadequate response in a month

⇒ If FBG 126 – 199 with associated condition

👉 Start drugs and life style modification

⇒ If FBG ≥ 200 regardless of associated condition

👉 Start drugs and life style modification

### Administer Drugs:

**Start with step-1, and go to next step if FBG ≥ 126 mg/dl (or RBG ≥ 200mg/dl)**

#### Diabetes with or without associated conditions:

Step 1:

⇒ Metformin (if renal insufficiency, start with step-2)

Step 2:

⇒ Add Sulphonylureas (if pregnant, skip step-2)

Step 3:

⇒ Add insulin therapy to oral drugs.

Step-4:

⇒ Label as non-responding diabetes, and refer.

**Note:** Other available oral hypoglycemic agents are not included in the regimen because of their non-inclusion in the essential drug list. See Appendix-2 for new oral hypoglycemic agent e.g. thiazolidinedione & DPP-4 inhibitor

## Prescribe oral anti-diabetic drugs

Drug			Daily dose (mg)				Comment
Class	Name	Tablet	Initial	Add <sup>#</sup>	Maint.	Max. /day	
Biguanides	Metformin	250mg 500mg 850mg 1g	500	500	500- 2550	3000	B.D or T.i.D
Sulphonyl- ureas	Glibencl- amide	2.5mg 5mg	5	5	10-15	15	O.D
	Gliclazide <sup>#</sup>	80mg	40	40	40-80	320	O.D or B.D
	Glimepride <sup>#</sup>	1mg 2mg 3mg 4mg	1-2	1	1-4	8	O.D

#: Gliclazide and Glimepride are not currently included in essential drug list.

## Administer Insulin

Insulin regimen	Type / dose of Insulin	Administration
Insulin augmentation	Long acting (glargine) 0.15 units / kg weight	⇒ Continue oral agents at the same dosage. ⇒ Add single injection of long acting insulin at bed time. (start with 10 units, then every 3 <sup>rd</sup> day add 2 units till FBG ≤125 or 40 units limit is reached)
Insulin replacement: conventional (to be initiated at hospitals only)	Combination of Regular + intermediate acting (NPH) 0.5U/Kg body weight	⇒ Two injections per day (one before breakfast and other before dinner) are given. ⇒ 2/3 of the calculated dose is given in the morning and 1/3 in the evening.



## Follow up – Hypertension and/or Type-2 Diabetes

### Monthly Follow-up for Continued Treatment:

- ⇒ Assess the adherence?
  - Ask patient adherence to the prescribed drugs
  - Verify adherence - check empty strips of drugs
  - Address non-adherence – counsel
- ⇒ Assess clinical condition (including signs of side effects)
  - Check BP, pulse, and edema
  - Ask and respond to the new complaint(s):
    - ✎ Adjust dose of: anti-hypertensive if: hypotension, edema, muscle weakness, anxiety, and anti-hyperglycemic if: hypoglycemia
    - ✎ Refer to specialist if: signs of HF or preeclampsia (in pregnant)
    - ✎ Stop drugs and refer to specialist if: jaundice, or fast and deep breathing, or severe muscle pain
- ⇒ Investigate:
  - Check every month:
    - Urine for protein (refer for kidney care if proteinuria worsens)
    - Blood for glucose (only if diabetic)
  - Check every 6 months:
    - Serum cholesterol - if baseline  $\geq 200$  mg/dl or CVD risk factor.
    - ALT\* - if on simvastatin (ALT is first tested at the end one-month)
- ⇒ Educate for lifestyle and treatment (as required)
  - The patients advised for smoking cessation are followed monthly for four months and then evaluated at 1year.
- ⇒ Prescribe:
  - ✎ Same regimen, if adequate response and no side effect
  - ✎ Adjusted regimen, if inadequate response or side effects
  - ✎ Stop simvastatin - if ALT rises three times than the baseline.
- ⇒ Maintain record
  - ✎ Enter data in “Chronic Disease Card”.

### Annual Assessment:

- ⇒ Eye examination (for retinopathy)
- ⇒ Examine for peripheral neuropathy
- ⇒ Blood glucose (for a non-diabetic hypertensive)

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\*ALT normal range: Males= 10-40IU/L, Females= 7-35IU/L

## Manage severe condition - complaint and vital sign abnormality

### CVD-Complaints

⇒ If chest pain > half hour at rest (MI); or few minutes exercise, going away at rest (angina)

👉 Administer the following, then refer to hospital:

✓ sublingual nitroglycerine (0.5mg) - one tablet asap, then one tablet every five minutes if pain persists (i.e. maximum 3 tablets in 12 hours).

*Contraindication:* chest pain with hypotension

✓ aspirin (300mg) - one tablet (even if 75mg preventive intake reported)

*Contraindication:* BP>180/110, or reported allergy to aspirin.

✓ oxygen administration – after pulse oximetry or may be clinical signs: inability to breathe, cyanosis of lips and nails, and confusion.

✓ opioid injectable analgesics considered, if severe pain.

*Contraindication:* if SBP<90 or respiratory rate<10/ minute.

⇒ If shortness of breath and ankle swelling (heart failure)

👉 Administer oxygen and diuretics (if no hypotension), then refer.

⇒ If sudden one-sided weakness/ slurred speech/ face drooping/ numbness (stroke)

👉 Restrict oral intake, maintain I/V, and maintain airway (only if altered consciousness), then refer.

⇒ If peripheral vascular disease (PAD) with danger signs: pain, pallor, pulseless, paresthesia, and paralysis of limb.

👉 Maintain I/V line, administer oxygen, and then refer to hospital (Note: do not elevate the extremity)

⇒ If dry gangrene

👉 Maintain I/V line, then refer for surgical debridement and I/V antibiotic.

### **Additional comments:**

⇒ If pneumothorax: administer oxygen, establish I/V line (needle thoracostomy for tension pneumothorax), then refer.

⇒ If asthma: administer bronchodilator and steroid (refer if status asthmaticus)

⇒ If altered consciousness because of injury (history), infection (fever with stiff neck), intoxication or poisoning (history), manage accordingly.

## Manage severe conditions – continued

- ⇒ If altered consciousness (with RBG: >360mg/dl and dehydration)
  - ✎ Infuse 2 liter normal saline in one hour, and administer insulin I/V infusion or subcutaneous (0.1 unit per kg) to achieve 250 – 300mg/dl, then refer
- ⇒ If severe hypoglycemia with altered consciousness (with RBG: <70mg/dl)
  - ✎ Administer I/V (in ≤10 minutes): 20ml of 50% dextrose or 200ml of 5% dextrose, repeat after 15 minutes if target (≥90mg/dl) is not achieved.

### **Vital sign abnormality**

- ⇒ If pulse: > 120/min and patient feel fainting
  - ✎ Loosen the clothing/belts/collars, elevate feet, and maintain airway. Do CPR (if required), then refer.
- ⇒ If systolic BP: > 200 mm of Hg (with signs of CVD)
  - ✎ Administer intravenous vasodilator or calcium channel blockers, then refer
    - ✓ sodium nitroprusside: 2.5 – 5 mcg/kg in 10 minutes (not if renal failure) (monitor BP every minute) OR
    - ✓ Diazoxide 100 mg every five minutes (not if heart failure) OR
    - ✓ Clevidipine: 1 – 2mg per hour in infusion.
- ⇒ If systolic BP: > 200 mm of Hg (without signs of CVD)
  - ✎ Administer oral beta blocker or ACE inhibitors, then refer
    - ✓ Labetalol: 100mg twice a day OR
    - ✓ Captopril: 25mg twice or thrice a day
- ⇒ If systolic BP: < 90 mm of Hg (shock)
  - ✎ Administer drugs and fluids, then refer
    - ✓ Dopamine (if BP:70-90): I/V infusion 5mcg/kg/min, OR
    - ✓ Nor-epinephrine (if BP <70): I/V infusion 2 – 4 mcg/min
    - ✓ I/V normal saline or Ringers lactate (only if non-cardiogenic)
- ⇒ If respiratory rate: > 20/ min (shortness of breath)
  - ✎ Upright the position and give low flow oxygen at 2L/min, then refer.

### **Additional comments:**

- ⇒ If non-cardiogenic shock – adjust the management accordingly and refer.
- ⇒ Rapid breathing - main conditions include heart failure, anxiety, pulmonary embolism, diabetic ketoacidosis, pneumonia, COPD, asthma, pneumothorax.

## Appendix 1

### Other Anti Hypertensive Drugs

Drug			Daily dose (mg)				Comment
Class	Name	Tablet	Initial	Add <sup>#</sup>	Maint.	Max./day	
CCB	Diltiazem	30mg 60mg 90mg	60	30	60-120	360	B.D or T.i.D
	Verapamil	40mg 80mg 240mg	40	40	40-80	480	T.i.D or q.i.d
	Nifedipine (retard)	20mg	20	20	20-40	90	B.D
ACE inhibitor	Captopril	12.5mg 25mg 5mg	12.5	12.5	6.25-25	50	B.D
	Enalapril	5mg 10mg 20mg	5	5	10-20	40	O.D
	Lisinopril	5mg 10mg 20mg	2.5	2.5	10-20	40	O.D
Beta Blocker	Carvedilol	6.25mg 12.5mg 25mg	12.5	12.5	12.5-25	50	O.D or B.D
Loop diuretic	Furosemide	20mg 40mg	20	20	20-40	80	O.D or B.D
ARBs	Losartan potassium	25mg 50mg	50	50	50-100	100	O.D

## Appendix 2

### Other Oral Anti Diabetic Drugs

Drug			Daily dose (mg)				Comment
Class	Name	Tablet	Initial	Add <sup>#</sup>	Maint.	Max./day	
Alpha-glucosidase inhibitors	Acarbose		25	25	50-100	300	T.i.D
Thiazolidine dione	Pioglitazone	15mg 30mg 45mg	15	15	15-30	45	O.D
DPP-4 inhibitors	Sitagliptin	50mg 100mg 500mg 1g	100				O.D

## Appendix 3

### Target weight for height chart

Height (feet, inches)	Target weight (kg)	
	Male	Female
4'6"	35	35
4'7"	39	37
4'8"	40	40
4'9"	44	42
4'10"	46	45
4'11"	50	47
5'0"	53	50
5'1"	55	52
5'2"	59	55
5'3"	61	57
5'4"	65	60
5'5"	68	62
5'6"	70	65
5'7"	74	67
5'8"	76	70
5'9"	80	72
5'10"	83	75
5'11"	85	77
6'0"	89	80
6'1"	91	83
6'2"	93	85
6'3"	96	88

## Appendix 4

Drugs	Major Side effect	Management
<b>Anti-diabetic</b>		
Metformin	<u>Lactic acidosis:</u> <ul style="list-style-type: none"> <li>• breathing: rapid and short,</li> <li>• heart: rapid rate;</li> <li>• abdomen: vomiting and pain;</li> <li>• mental: anxiety, weakness</li> </ul>	Stop the drug and seek expert advice.
Sulphonylureas and insulin	<u>Severe hypoglycemia:</u> <ul style="list-style-type: none"> <li>• skin: sweating, cold</li> <li>• heart: rapid rate, palpitations</li> <li>• mental: nervousness, anxiety, weakness</li> <li>• abdomen: nausea, hunger</li> </ul>	
<b>Anti-hypertensive</b>		
ACE inhibitors	<u>Angio-edema:</u> <ul style="list-style-type: none"> <li>• face: swelling (especially in and around mouth)</li> <li>• hands: swelling, and itchy and painful.</li> <li>• Skin: reddish marks</li> <li>• breathing: wheezing or shortness</li> <li>• mental: altered consciousness</li> </ul> <u>Hyperkalemia:</u> <ul style="list-style-type: none"> <li>• heart: palpitation</li> <li>• mental: uneasiness</li> </ul>	Stop the drug and seek expert advice.

	<ul style="list-style-type: none"> <li>• muscle: weakness</li> <li>• breathing: mildly rapid</li> </ul>	
Diuretic	<u>Arrythmia:</u> <ul style="list-style-type: none"> <li>• heart: palpitation and discomfort</li> <li>• mental: fatigue, dizziness, fainting</li> <li>• breathing: shortness</li> </ul>	
<b>Preventive treatment</b>		
Statin	<ul style="list-style-type: none"> <li>• Severe muscle pain</li> </ul>	Stop the drug and seek expert advice.
<b>Any of the above three</b>		
	<u>Moderate to severe allergic reaction:</u> <ul style="list-style-type: none"> <li>• Skin: rashes/itching</li> <li>• Breathing: wheezing, difficulty</li> <li>• Mental: altered consciousness (in severe)</li> </ul>	Stop the drugs and seek expert advice.



This guide, as a decision-aid, does not cover all possible situations and/or solutions related with the management of hypertension-CVD and type-2 diabetes. The clinical judgment of the doctor remains the basis for final decision-making, and this aid should only be taken as a supplement and not a substitute of the clinical acumen. The desk guide contents, based on international guidelines, have been contextualized to the operational circumstances, through in-country working group process. The main guidelines consulted for the exercise include:

- WHO (2007): Prevention of cardiovascular disease - Guidelines for assessment and management of cardiovascular risk.
- NICE (2011): Clinical management of primary hypertension in adults (127)
- JNC-7 Express (2003): Prevention, detection, evaluation and treatment of high blood pressure
- IDF (2005): Global guidelines for type-2 diabetes
- NICE (2009): The management of type-2 diabetes (66)

**Developed by:**

- Directorate General of Health Services Punjab, Pakistan.
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Nuffield

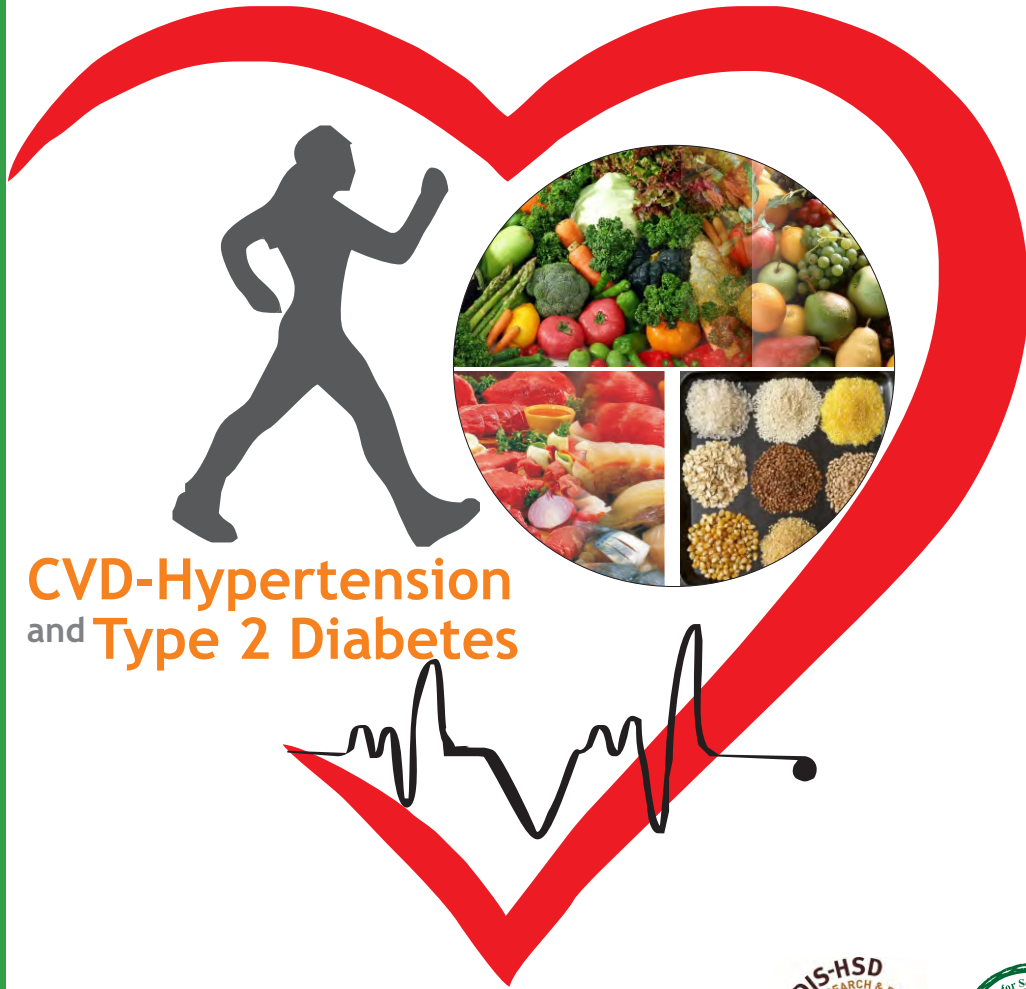


ASD



DGHS

# Life Style Counseling



CVD-Hypertension  
and Type 2 Diabetes



Nuffield

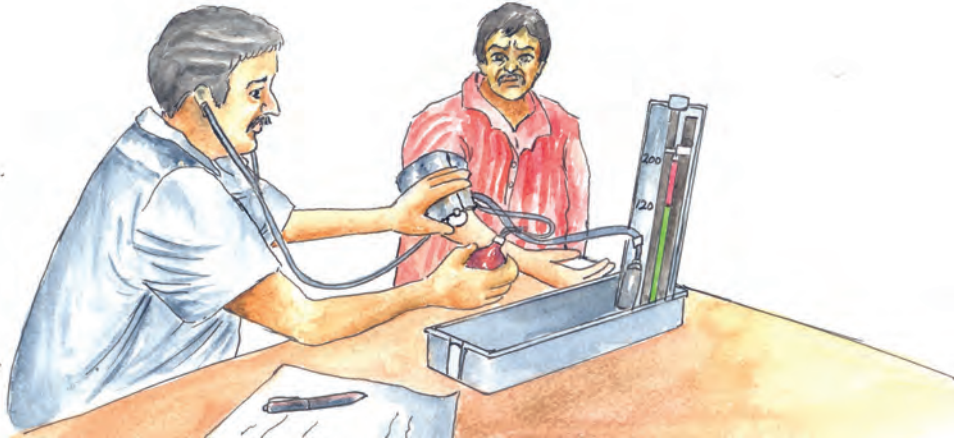


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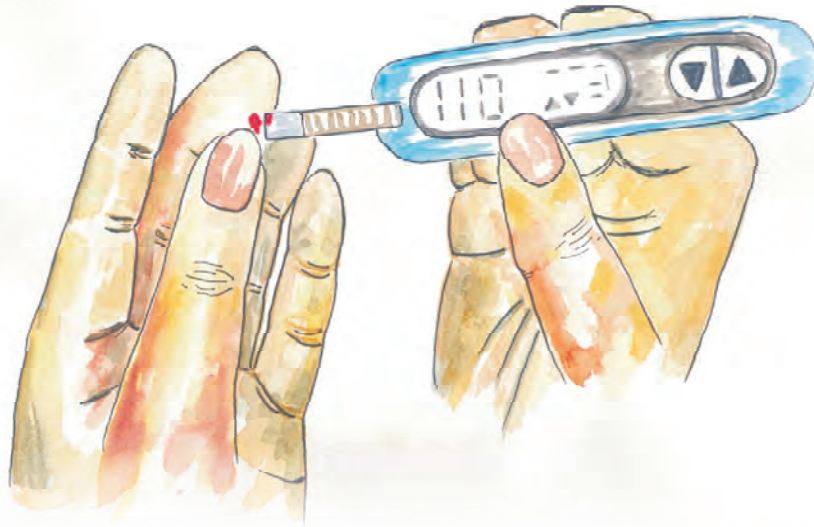


Prevention & Control:  
NCDs & Mental Health

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## سلائیڈ 1

### بلڈ پریشر کے بڑھاؤ اور ذیابیطس کا تعارف

- خاکہ نمبر 1: بلڈ پریشر  
مریض سے پوچھیں  
آپ کے خیال میں خاکہ نمبر 1 کس بیماری کے معائنہ کی نشاندہی کرتا ہے۔  
مریض کی رہنمائی کریں  
بلڈ پریشر کے بڑھاؤ کا معائنہ۔  
مریض سے پوچھیں  
آپ کے خیال میں بلڈ پریشر کے بڑھاؤ کا مرض کیا ہوتا ہے۔  
مریض کی رہنمائی کریں  
نالیوں میں خون کے دباؤ میں غیر معمولی اضافہ بلڈ پریشر کا بڑھاؤ کہلاتا ہے۔

- خاکہ نمبر 2: ذیابیطس  
مریض سے پوچھیں  
آپ کے خیال میں خاکہ نمبر 2 کس بیماری کے معائنہ کی نشاندہی کرتا ہے۔  
مریض کی رہنمائی کریں  
خون میں شوگر (شکر) کا معائنہ برائے ذیابیطس۔  
مریض سے پوچھیں  
آپ کے خیال میں ذیابیطس کا مرض کیا ہوتا ہے۔  
مریض کی رہنمائی کریں  
خون میں شوگر (شکر) کی غیر معمولی زیادتی ذیابیطس کہلاتی ہے۔

- حتمی پیغام:  
1 نالیوں میں خون کے دباؤ میں غیر معمولی اضافہ بلڈ پریشر کا بڑھاؤ کہلاتا ہے۔  
2 خون میں شوگر (شکر) کی غیر معمولی زیادتی ذیابیطس کہلاتی ہے۔ یہ دونوں امراض غیر متعدی ہیں۔

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## سلائیڈ 2

### بلڈ پریشر کے بڑھاؤ اور ذیابیطس کے خطرے کو بڑھانے والے عوامل

مریض سے پوچھیں دیے گئے خاکوں میں روزمرہ زندگی کے کن عوامل کی نشاندہی کی گئی ہے جو بلڈ پریشر کے بڑھاؤ اور ذیابیطس کے خطرے کو بڑھاتے ہیں۔

- خاکہ نمبر 1: موٹاپا
- خاکہ نمبر 2: ورزش کی کمی
- خاکہ نمبر 3: زائد گھی / خوردنی تیل کا استعمال
- خاکہ نمبر 4: زائد نمک کا استعمال
- خاکہ نمبر 5: سگریٹ نوشی
- خاکہ نمبر 6: غیر صحت مند خوراک کا استعمال

مریض کی رہنمائی کریں دیے گئے خاکوں کو سمجھنے اور اپنی روزمرہ زندگی کے معمولات کا جائزہ لینے میں مدد کریں۔ (معمولات جن کی نشان دہی ہو ان کو یاد رکھنے کے طریقہ کار میں مدد کریں)

موٹاپا، ورزش کی کمی، گھی اور نمک کا زائد استعمال، سگریٹ نوشی اور غیر صحت مند خوراک کا استعمال بلڈ پریشر کے بڑھاؤ اور ذیابیطس کے خطرے کو بڑھاتے ہیں۔

حتمی پیغام:

## بیماری پر قابو نہ پانے کے ممکنہ نتائج

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### سلائیڈ 3

## بلڈ پریشر کے بڑھاؤ اور ذیابیطس پر قابو نہ پانے کے ممکنہ نتائج

مریض سے پوچھیں دیے گئے چار خاکوں میں بیماری پر قابو نہ پانے کے کن ممکنہ نتائج کی نشاندہی کی گئی ہے۔

خاکہ نمبر 1: گردوں کا مرض

خاکہ نمبر 2: دل کا دورہ

خاکہ نمبر 3: اندھاپن

خاکہ نمبر 4: فالج

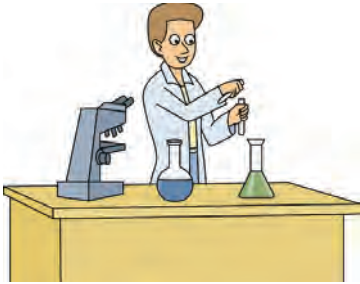
خاکہ نمبر 5: پاؤں کے زخم کا بگڑ جانا

مریض کی رہنمائی کریں دیے گئے ممکنہ نتائج کے خاکوں کو سمجھنے میں مدد کریں۔

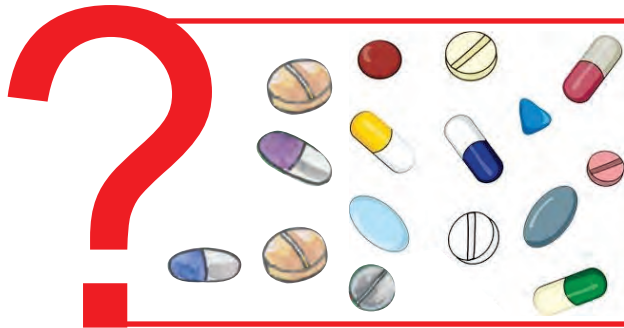
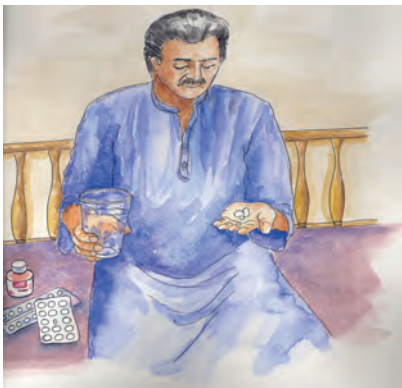
حتمی پیغام: بیماری کی ممکنہ پیچیدگیوں سے بچاؤ کے لیے کامیاب علاج اور صحت مند انداز زندگی ضروری ہے۔



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#### سلائیڈ 4

### بلڈ پریشر کے بڑھاؤ اور ذیابیطس پر قابو پانے کے لیے باقاعدہ علاج

مریض سے پوچھیں دیے گئے دو خاکوں میں کامیاب علاج کے لیے کن عوامل کی نشاندہی کی گئی ہے۔

خاکہ نمبر 1: مرکز صحت سے حسب معمول اور شکایت کی صورت میں فوری رابطہ کی اہمیت:

- طبی اور لیبارٹری ٹیسٹ کی مدد سے بیماری کو قابو میں رکھا جائے تاکہ دوائی جاری رہے یا شکایت کی صورت میں خوراک میں ردوبدل کیا جاسکے۔
- بقائیدگی سے دوائی کے استعمال کا تعین کرنا اور ضرورت پڑنے پر روزمرہ زندگی کے معلومات میں باہمی مشورہ سے ردوبدل کرنا۔
- دوا کے نئے نسخہ اور مریض کو اگلے مہینے کی دوا فراہم کرنا۔
- ماہانہ معاینے یا بیماری میں پیچیدگی کی علامات ظاہر ہونے کی صورت میں مریض کو ڈاکٹر سے رجوع کا کہیں۔

خاکہ نمبر 2: تجویز کردہ دوا کی:

- پیچان کروائیں
- خوراک میں گولیوں کی تعداد
- دن میں خوراک کی مقدار
- دوا کھانے سے پہلے / بعد پانی کے ساتھ لیں

مریض کی رہنمائی کریں دیے گئے علاج کے خاکوں کو سمجھنے میں مدد کریں۔

تجویز کردہ دوا کا روزانہ کھانا، مرکز صحت پر ماہانہ معائنہ اور شکایت کی صورت میں فوری رابطہ کامیاب علاج کے لیے ضروری ہیں۔

حتمی پیغام:

## ذیابیطس کے زیر علاج مریض میں شوگر کی ممکنہ کمی کی دیکھ بھال



دوران علاج شوگر کی کمی ہو سکتی ہے۔ جس میں فوری طور پر میٹھی اشیاء کا استعمال ضروری ہے۔

## ذیابیطس میں پاؤں کی دیکھ بھال



## سلائیڈ 5

### ذیابیطس کے زیر علاج مریض میں شوگر کمی کی ممکنہ کمی کی دیکھ بھال

مریض سے پوچھیں دیے گئے چار خاکوں میں زیر علاج مریض میں شوگر کمی کی کن علامات کی نشاندہی کی گئی ہے۔

خاکہ نمبر 3: پسینہ آنا

خاکہ نمبر 5: سردرد

خاکہ نمبر 4: دل کی دھڑکن تیز محسوس ہونا

خاکہ نمبر 6: چڑا چڑاپن

مریض کی رہنمائی کریں زیر علاج مریض میں شوگر کمی کی ممکنہ علامات کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں دیے گئے تین خاکوں میں شوگر کمی میں کن فوری میسر میٹھی اشیاء کی نشاندہی کی گئی ہے۔

● شہد، چینی یا شکر کا چمچ ● میٹھے مشروبات یا دودھ ● ٹوفی

مریض کی رہنمائی کریں شوگر کمی کی علامات کے لیے میسر میٹھی اشیاء کا فوری استعمال کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں دیے گئے چار خاکوں میں ذیابیطس میں پاؤں کی حفاظت کی کن اقدامات کی نشاندہی کی گئی ہے۔

خاکہ نمبر 1: پاؤں کی صفائی (خشک رکھنا)

خاکہ نمبر 2: ناخن کاٹنے میں احتیاط

خاکہ نمبر 3: بند جوتے کا استعمال

خاکہ نمبر 4: ننگے پاؤں پھرنے سے پرہیز

مریض کی رہنمائی کریں دیے گئے حفاظتی اقدامات کے خاکوں کو سمجھنے میں مدد کریں۔

1 زیر علاج مریض میں شوگر کمی کی علامات میں میسر میٹھی اشیاء کا فوری استعمال کریں۔

2 ذیابیطس میں پیروں کو صاف ستھرا رکھنا اور ان کو چوٹ سے بچانا ضروری ہے۔

حتمی پیغام:

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## سلائیڈ 6

### بلڈ پریشر کے بڑھاؤ اور ذیابیطس کے مرض پر قابو پانے کے لیے صحت مند انداز زندگی

مریض سے پوچھیں دیے گئے خاکوں میں روزمرہ زندگی کے کن عوامل کی نشاندہی کی گئی ہے جو بلڈ پریشر کے بڑھاؤ اور ذیابیطس کے مرض پر قابو (کنٹرول) پانے کے لیے ضروری ہیں۔

- خاکہ نمبر 1: کم نمک کا استعمال (6 افراد خانہ کے کھانے کے لیے ایک چائے کا چمچ نمک)
- خاکہ نمبر 2: کم خوردنی تیل کا استعمال (6 افراد خانہ کے کھانے کے لیے دو کھانے کے چمچ تیل)
- خاکہ نمبر 3: روزانہ 30 منٹ تیز چلنا
- خاکہ نمبر 4: سگریٹ نوشی ترک کرنا \*
- خاکہ نمبر 5: غیر صحت مند خوراک سے پرہیز

مریض کی رہنمائی کریں دیے گئے خاکوں کو سمجھنے اور روزمرہ زندگی پر اطلاق کی منصوبہ بندی کرنے میں مدد کریں۔ (روزمرہ معمولات میں تبدیلی کی رضامندی، ممکنہ رکاوٹیں اور ان کا متفقہ حل)

\* تمباکو نوشی ترک کرنے کے لیے رضا مند افراد کو مدد کے لیے متعلقہ کارکنان صحت کے پاس بھیجیں۔

روزانہ 30 منٹ تیز چلنا، کھانے میں خوردنی تیل 1 گھی اور نمک کا کم استعمال، سگریٹ نوشی اور غیر صحت مند خوراک سے پرہیز بلڈ پریشر کے بڑھاؤ اور ذیابیطس کے مرض پر قابو پانے کے لیے ضروری ہیں۔

حتمی پیغام:



## صحت منداشیاء خوراک کی نشاندہی

مریض سے پوچھیں دیے گئے خاکوں میں کن صحت منداشیاء خوراک کی نشاندہی کی گئی ہے

خاکہ نمبر 1: سبزیاں۔

خاکہ نمبر 2: دالیں۔

خاکہ نمبر 3: پھل۔

مریض کی رہنمائی کریں دیے گئے صحت منداشیاء خوراک کے خاکوں کو سمجھنے میں مدد کریں۔

سبزی، دال اور پھل کا روزانہ استعمال کریں

حتمی پیغام:





اناج



گوشت



گری دار  
میوه جات



ڈیری  
مصنوعات

## صحت کے لیے مفید اشیاء خوراک کی نشاندہی

مریض سے پوچھیں دیے گئے خاکوں میں کن مفید اشیاء خوراک کی نشاندہی کی گئی ہے

خاکہ نمبر 1: اناج

خاکہ نمبر 2: گوشت

خاکہ نمبر 3: ڈیری مصنوعات

خاکہ نمبر 4: گری دارمیوہ جات

مریض کی رہنمائی کریں دیے گئے صحت کے لیے مفید اشیاء خوراک کے خاکوں کو سمجھنے میں مدد کریں۔

اناج، گوشت، ڈیری مصنوعات اور گری دارمیوہ جات اعتدال سے استعمال کریں۔

حتمی پیغام:



## مضر صحت اشیاء خوراک کی نشاندہی

مریض سے پوچھیں دیے گئے خاکوں میں کن مضر صحت اشیاء خوراک کی نشاندہی کی گئی ہے

خاکہ نمبر 1: میٹھی اشیاء خورد (مٹھائی، کیک اور آئس کریم)۔

خاکہ نمبر 2: تلی ہوئی اشیاء۔

خاکہ نمبر 3: میٹھے مشروبات۔

مریض کی رہنمائی کریں دیے گئے مضر صحت اشیاء خوراک کے خاکوں کو سمجھنے میں مدد کریں۔

حتمی پیغام: میٹھی اشیاء، تلی ہوئی اشیاء اور میٹھے مشروبات ہفتے میں ایک بار سے زائد استعمال مت کریں۔

## سالن



سبزی



دال



گوشت



انڈہ

## اناچ



روٹی



چاول



دلیہ



ٹوسٹ

## روزمرہ استعمال کے مشروب



قہوہ



چائے



دودھ

## متوازن کھانے کے بارے میں آگاہی

- مریض سے پوچھیں دیے گئے تین خاكوں میں كن تيارا شياء خوراك كى نشاندہى كى گئى ہے
- خاكہ نمبر 1: ایک پلیٹ سالن (سبزی، دال، گوشت) ایک انڈہ۔
- خاكہ نمبر 2: اناج (ایک روٹی، ایک پلیٹ چاول، دلیہ، دوٹوسٹ)۔
- خاكہ نمبر 3: روزمرہ استعمال كے مشروب (دودھ، چائے، قہوہ)۔

مریض كى رہنمائى كریں دیے گئے تيارا شياء خوراك كے خاكوں كو سمجھنے میں مدد كریں۔

مریض سے پوچھیں خاكوں میں دیے گئے تيارا شياء خوراك كا استعمال كس طرح كریں گے۔

مریض كى رہنمائى كریں ایک وقت كے كھانے میں ایک اناج اور ایک سالن تجویز كردہ مقدار میں استعمال كریں۔

- 1 ناشتے، دوپہر اور رات كے كھانوں میں سالن اور اناج كى تجویز كردہ مقدار استعمال كریں۔
- 2 بغیر چینی دودھ دن میں ایک مرتبہ اور چائے و قہوہ چھ مرتبہ تک استعمال كرسکتے ہیں۔

حتمی پیغام:

HEIGHT (feet, inches)	TARGET WEIGHT (kg)		HEIGHT (feet, inches)	TARGET WEIGHT (kg)	
	Male	Female		Male	Female
4'6"	35	35	5'5"	68	62
4'7"	39	37	5'6"	70	65
4'8"	40	40	5'7"	74	67
4'9"	44	42	5'8"	76	70
4'10"	46	45	5'9"	80	72
4'11"	50	47	5'10"	83	75
5'0"	53	50	5'11"	85	77
5'1"	55	52	6'0"	89	80
5'2"	59	55	6'1"	91	83
5'3"	61	57	6'2"	93	85
5'4"	65	60	6'3"	96	88

*This material can be freely used by the national programmes and 'not-for-profit' organizations involved in the delivery of Hypertension-CVD and Type II Diabetes- care . Profit-making organizations that wish to use the material are invited to contact the Association for Social Development for permission.*

**Comments / information:**

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Ph: (92-51) 2611230-3 Fax: (92-51) 2655639 Email: asd@asd.com.pk

# ترقی کتابچہ

## Smoking Cessation



# ترک تمباکو نوشی کے پانچ مراحل



UNIVERSITY OF LEEDS

Nuffield

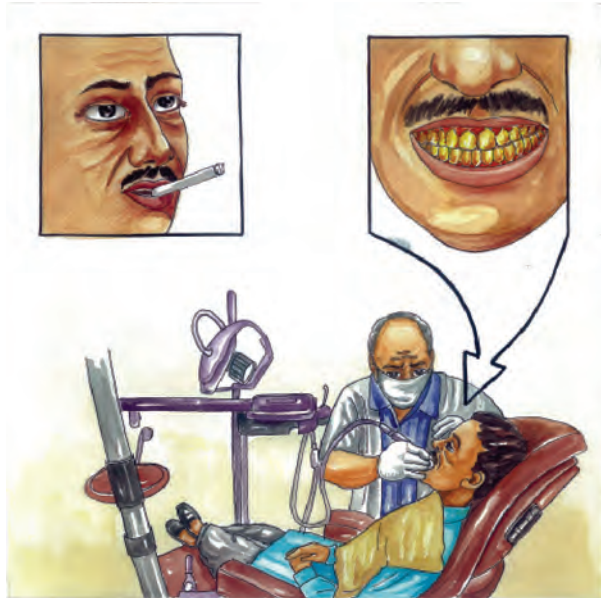


ASD



Prevention & Control:  
NCDs & Mental Health





مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

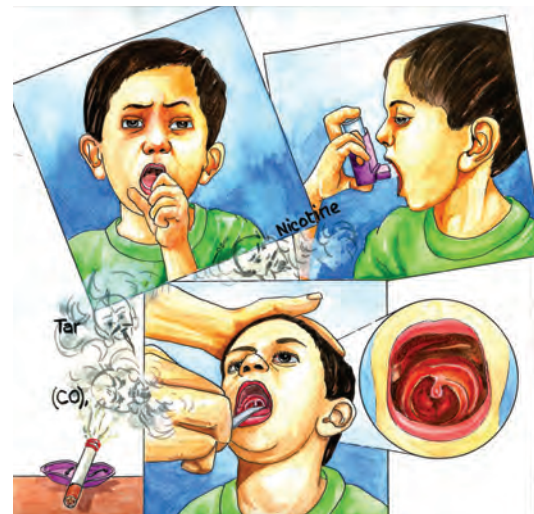
- 1 سگریٹ پینے والا شخص کو دل کا درد محسوس ہو رہا ہے اور اس کو دل کا دورہ پڑا اب وہ ہسپتال میں ہے۔
- 2 ڈاکٹر مریض کے ایکسرے میں خرابی دیکھ رہا ہے۔
- 3 پھیپھڑوں میں کینسر (سرطان) کا نشان۔
- 4 دانتوں کا ڈاکٹر مریض کا معائنہ کر رہا ہے اور دانت پیلے اور مسوڑھے خراب اور مریض کے منہ سے بو محسوس ہو رہی ہے۔

مریض کی رہنمائی کریں تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض کی رہنمائی کریں حتمی پیغام کے بارے میں وضاحت کریں۔

حتمی پیغام: تمباکو نوشی بلڈ پریشر کی زیادتی اور دل کا دورہ، پھیپھڑوں کی شدید بیماریوں (دائمی کھانسی، دمہ، ٹی بی) اور پھیپھڑوں کے سرطان کا باعث بن سکتی ہے۔ تمباکو نوشی سے دانت بدنما اور مسوڑھے خراب ہو جاتے ہیں جس کی وجہ سے منہ سے بدبو آتی ہے



مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

1 آدمی گھر میں سگریٹ پی رہا ہے، بچے اور اہل خانہ دھوئیں سے متاثر ہو رہے ہیں۔

خاکہ نمبر 2

1 حاملہ خاتون حقہ پی رہی ہے۔

2 خاتون ہسپتال میں داخل ہے۔

3 کمزور اور لاغر بچے کی پیدائش ہوئی ہے۔

مریض کی رہنمائی کریں تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض کی رہنمائی کریں حتمی پیغام کے بارے میں وضاحت کریں۔

حتمی پیغام: 1 تمباکو نوشی کا دھواں خود آدمی کے لئے اور اس کے اہل خانہ کے لیے یکساں طور پر مضر صحت ہے۔ ایسے گھرانے کے بچوں کا نمونیہ، دمہ اور دیگر بیماریوں میں مبتلا ہونے کا امکان بھی زیادہ ہوتا ہے۔

2 خواتین میں تمباکو نوشی حمل میں پچدگی اور لاغر اور کمزور بچے کی پیدائش کا باعث بن سکتی ہے۔



مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

1 کیلنڈر پر 9 تاریخ تک سگریٹ بنے ہوئے ہیں، آدمی 9 تاریخ پر کاٹا لگا رہا ہے اور سگریٹ کی ڈبیہ کوڑا دان میں پھینک رہا ہے۔ 9 تاریخ کے بعد کیلنڈر پر فروٹ اور کھانے کی چیزیں بنی ہیں۔

خاکہ نمبر 2

1 بچے اور اہل خانہ سگریٹ نوشی کے دھوئیں سے پیدا ہونے والے امراض سے محفوظ اور صحت مند نظر آ رہے ہیں۔

2 گھر میں فروٹ، ٹی وی، فریج اور بچوں کے پاس کھلونے ہیں۔

مریض کی رہنمائی کریں تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض کی رہنمائی کریں حتمی پیغام کے بارے میں وضاحت کریں۔

حتمی پیغام: 1 تمباکو نوشی چھوڑنے کا مضبوط ارادہ اور تاریخ کا انتخاب کریں۔

2 بچنے والے پیسوں کو بہتر مصرف میں لائیں۔

3 تمباکو نوشی ترک کرنے سے آپ کے معاشی حالات میں بہتری آئے گی اور آپ اور

آپ کے اہل خانہ صحت مند اور خوشحال زندگی گزاریں گے



مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

1 صبح کا وقت اور جاگنے کے بعد آدمی کی سگریٹ پر نظر

2 آدمی باتھ روم جاتے ہوئے سگریٹ ساتھ لے جا رہا ہے

خاکہ نمبر 2

1 تمباکو نوشی کے بجائے کسی مشروب کا استعمال کرنا 2 دانت صاف کیے جا رہے ہیں

3 صبح کی سیر کی جا رہی ہے 4 اخبار پڑھا جا رہا ہے

5 آدمی باتھ روم جاتے ہوئے اخبار ساتھ لے جا رہا ہے

مریض کی رہنمائی کریں تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض کی رہنمائی کریں حتمی پیغام کے بارے میں وضاحت کریں۔

حتمی پیغام: 1 صبح جاگنے کے بعد تمباکو نوشی کی طلب ہونے پر آپ کوئی مشروب پی لیں، دانت

صاف کر لیں، صبح کی سیر پر چلیں جائیں یا پھر آپ اخبار پڑھ لیں

2 رفع حاجت کے لیے تمباکو نوشی کی عادت ہونے کی صورت میں آپ متبادل کے

طور پر اخبار پڑھ سکتے ہیں





مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

- 1 آدمی کھانا کھاتے ہوئے تمباکو نوشی کی طلب محسوس کر رہا ہے
- 2 آدمی کرسی پر فارغ بیٹھا سوچ رہا ہے اور تمباکو نوشی کی طلب محسوس کر رہا ہے

خاکہ نمبر 2

- 1 آدمی چیونگم کھا رہا ہے
- 2 آدمی سیر کر رہا ہے
- 3 آدمی آرام کر رہا ہے
- 4 آدمی باغبانی کر رہا ہے

مریض کی رہنمائی کریں  
تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں  
اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض کی رہنمائی کریں  
حتمی پیغام کے بارے میں وضاحت کریں۔

حتمی پیغام: کھانا کھانے کے بعد اور فارغ اوقات میں تمباکو نوشی کی طلب ہونے کی صورت میں آپ دھیان بٹانے کے لئے چیونگم استعمال کر لیں، سیر کر لیں یا تھوڑی دیر آرام کر لیں، کچھ دیر باغبانی کر لیں۔



مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

- 1 ایک آدمی بیٹھے ہوئے دیگر افراد کو تمباکو نوشی میں مشغول دیکھ رہا ہے
- 2 تمباکو نوشی کرنے والا فرد دوسرے آدمی کو سگریٹ پیش کر رہا ہے۔

خاکہ نمبر 2

- 1 دھیان بٹانے کے لیے آدمی چیونگم کا استعمال کر رہا ہے
- 2 دھیان بٹانے کے لیے آدمی گہرا سانس لے رہا ہے
- 3 آدمی تمباکو نوشی میں مشغول افراد کے ساتھ بات چیت کر رہا ہے
- 4 آدمی تمباکو نوشی کی پیشکش کو ٹھکرا رہا ہے

مریض کی رہنمائی کریں تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض سے پوچھیں اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض کی رہنمائی کریں حتمی پیغام کے بارے میں وضاحت کریں۔

حتمی پیغام: تمباکو نوشی میں مشغول افراد کو دیکھ کر سگریٹ کی طلب ہونے کی صورت میں آپ دھیان بٹانے کے لیے چیونگم کھا سکتے ہیں، سانس کی مخصوص ورزش کر لیں۔ تمباکو نوشی کی پیشکش پر ایسی پیشکش فوراً ٹھکرائیں۔ ایسے افراد کو تمباکو نوشی کے نقصات سے آگاہ کریں اور اسے ترک کرنے کا مشورے دیں۔



مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

1 آدمی کام کی زیادتی کی وجہ سے تمباکو نوشی کی طلب محسوس کر رہے ہیں۔

2 ایک آدمی پریشان بیٹھا ہوا ہے اور تمباکو نوشی کی طلب محسوس کر رہا ہے۔

خاکہ نمبر 2

دھیان بٹانے کے لیے

1 آدمی خشک میوہ جات کھا رہا ہے 2 آدمی ورزش کر رہا ہے

3 آدمی نماز میں مشغول ہے 4 آدمی دوسرے آدمی (دوست) کو اپنی پریشانی بتا رہا ہے

تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض کی رہنمائی کریں

اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض سے پوچھیں

حتمی پیغام کے بارے میں وضاحت کریں۔

مریض کی رہنمائی کریں

کام کی زیادتی اور کام کے دوران ٹھکاوٹ کے باعث تمباکو نوشی کی طلب ہونے پر

حتمی پیغام:

دھیان بٹانے کے لیے آپ خشک میوہ جات کھا سکتے ہیں، گہرے سانس کی مخصوص

ورزش کر سکتے ہیں، نماز پڑھ سکتے ہیں اور پریشانی کے باعث تمباکو نوشی کی طلب ہونے

پر اپنی پریشانی کے لیے کسی دوست احباب سے مشورہ کریں۔



مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

- 1 آدمی بہت سخت بے تاب ہے اور کسی وجہ سے بہت بے چینی میں ہے
- 2 ایک آدمی اہل خانہ کے ساتھ موجود ہے اور غصے کا اظہار کر رہا ہے
- 3 آدمی کو سر کا درد ہے جس کی وجہ سے اُس نے سر کو پکڑ رکھا ہے

خاکہ نمبر 2

دھیان بٹانے کے لیے

- 1 آدمی ورزش کر رہا ہے
- 2 آدمی دوسرے آدمی (دوست) سے بات چیت کر رہا ہے
- 3 آدمی نماز میں مشغول ہے
- 4 میز پر سردرد کی گولیاں (پیراسٹامول) اور پانی پڑا ہوا ہے

تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔

مریض کی رہنمائی کریں

اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔

مریض سے پوچھیں

حتمی پیغام کے بارے میں وضاحت کریں۔

مریض کی رہنمائی کریں

حتمی پیغام: تمباکو نوشی کی شدید طلب ہونے کی صورت میں اور تمباکو نوشی چھوڑنے کے بعد بار بار

غصہ آنے یا سردرد ہونے کی صورت میں سردرد کی گولی (پیراسٹامول) لے لیں،

آپ اپنے کسی دوست احباب کے ساتھ بات چیت کر لیں اور دھیان بٹانے کے لئے

سانس کی مخصوص ورزش کر لیں یا نماز پڑھ لیں۔





مریض سے پوچھیں

تصویر میں دیے گئے مندرجہ ذیل دو حصوں کی نشاندہی کرتے ہوئے مریض سے دریافت کریں۔

خاکہ نمبر 1

- 1 آدمی معدے کی جلن اور بد ہضمی کا شکار ہے۔
- 2 کھانے سے آدمی بیزاری کا اظہار کر رہا ہے۔
- 3 آدمی کو شدید کھانسی ہو رہی ہے۔
- 4 آدمی رفع حاجت میں قبض محسوس کر رہا ہے۔

خاکہ نمبر 2

- 1 آدمی ڈاکٹر سے مشورہ کر رہا ہے۔
- 2 آدمی باغ میں صبح کی سیر کر رہا ہے۔
- 3 آدمی کھانا کھا رہا ہے اور کھانے میں سبزیاں اور پھل زیادہ ہیں۔

مریض کی رہنمائی کریں  
تصویر کے ہر حصے کو سمجھنے میں مدد کریں۔  
مریض سے پوچھیں  
اس تصویر میں دیئے گئے اشاروں سے آپ کیا اخذ کرتے ہیں۔  
مریض کی رہنمائی کریں  
حتمی پیغام کے بارے میں وضاحت کریں۔

حتمی پیغام: تمباکو نوشی چھوڑنے کے بعد معدے کی جلن، بد ہضمی، کھانے کی چاہت ختم، قبض کی شکایت اور کھانسی کی تکلیف میں آپ چوسنے والی گولیاں کھالیں اور کھانے میں سبزیوں اور پھل کا استعمال زیادہ کریں۔ شکایت دور نہ ہونے کی صورت میں آپ ڈاکٹر سے رجوع کر سکتے ہیں۔ آپ صبح کی سیر کو معمول بنا سکتے ہیں۔



