# Adherence and Quality of Life of Patients with Type II Diabetes:

**Role of Psychosocial Factors** 

# A thesis submitted during July 2016 to the Centre for Health Psychology, School of Medical Sciences, University of Hyderabad, in partial fulfillment of the requirements for the award of the degree of **Doctor of Philosophy in Psychology**

by

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University of Hyderabad (P.O.) Central University, Gachibowli Hyderabad – 500046 Telangana, India To the Almighty God, my Creator, my Heavenly Father, a Constant Companion, in this intellectual and spiritual odyssey, who led me step by step, sustained me, strengthened me, to attain this goal and credibility, to fulfill the purpose of my life, I offer up this work.

# DECLARATION

I, PADIRI RUTH ANGIEL, hereby declare that this thesis entitled, "Adherence and Quality of Life of Patients with Type II Diabetes: Role of Psychosocial Factors", submitted by me under the guidance and supervision of Dr. MEERA PADHY, is a bonafide research work which is also free from plagiarism. I also declare that it has not been submitted previously in part or full, to this university or any other university or institution for the award of any degree or diploma. I hereby agree that my thesis can be deposited in Shodganga/ INFLIBNET.

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# ABSTRACT

Diabetes is a daily personal challenge for those suffering from the condition, along with being a major public health burden for India. Treatment and management for diabetes is complex, demanding, and a lifelong continuous process which can be overwhelming for the patients and strains their quality of life. Adherence is a major factor in managing diabetes to achieve optimal glycemic control and delay or reduce the risk of any diabetesrelated complications. The present study aimed to assess the difference in the level of social support, knowledge, self-efficacy, adherence, and quality of life among three groups of Type II diabetes patients categorized on the basis of duration of illness. It was also aimed to understand the role of social support, knowledge, and self-efficacy in adherence and quality of life of Type II diabetes patients. In phase I of the study, the pilot study was conducted to develop two new psychological instruments such as Diabetes Symptoms Checklist and Diabetes Knowledge Test for Indian Population and also to check the feasibility of the study. In phase II, the main study was conducted. In the main study, a correlational design was used to understand the relationship among the variables and the role of predictor variables on the criterion. Using purposive sampling method, 235 Type II diabetes patients both men and women, whose age range was from 25-75 years were included in this study. To assess the difference in the level of the variables under study, the sample was categorized into three groups based on the duration of illness, such as group I (one month to one year), group II (above one year to five years), and group III (above five years to 20 years). The instruments used to measure the variables under study were Clinical History Proforma, Diabetes Symptoms Checklist, The Diabetes Knowledge Test for Indian Population (DKT-I), Interpersonal Support

Evaluation List (ISEL), Stanford Self-efficacy Scale for Diabetes, Diabetes Adherence Scale (DAS), and Diabetes-39 Quality of Life Questionnaire. These instruments were administered in two sessions to the patients. Results showed that the three groups differed significantly, on few of the variables namely knowledge of diabetes, self-efficacy, adherence and quality of life. After ascertaining that there exists a relationship between the variables, subsequent analyses were conducted to assess the role of the predictor variables in the criterion variables. It was found that the only significant positive and independent predictor contributing to overall adherence was self-efficacy. And the significant independent predictors contributing to overall quality of life were overall diabetes knowledge, self-efficacy and adherence. A pathway was depicted to illustrate the influence of the identified predictor variables on the criterion variables, and it was noticed that self-efficacy played a major role in both adherence and quality of life of Type II diabetes patients. The implications, strengths and limitations of the study are also discussed.

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# LIST OF ABBREVIATIONS

ADA	American Diabetes Association
BMI	Body Mass Index
CBT	Cognitive Behavior Therapy
DAS	Diabetes Adherence Scale
DKN	The Diabetes Knowledge Assessment
DKQ	The Diabetic Knowledge Questionnaire
DKT–I	The Diabetes Knowledge Test For Indian Population
DNT	The Diabetic Numeracy Test

DSME/S	Diabetes Self-Management Education and Support
HbA1c	Glycosylated Hemoglobin
HBM	The Health Belief Model
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
HRQOL	Health-Related Quality of Life
ICMR-INDIAB	Indian Council of Medical Research- India-Diabetes
IDF	International Diabetes Federation
IFG	Impaired Fasting Glucose
ISEL	Interpersonal Support Evaluation List
MDKT	The Michigan Diabetes Knowledge Test
MI	Motivational Interviewing
PWB	Psychological Well-Being
QOL	Quality of Life
Sanofi SITE	Sanofi- Screening India's Twin Epidemic
SDM	Shared Decision-Making

- SRM The Self-Regulation Model
- SWB Subjective Well-being

- TPB The Theory of Planned Behavior
- World Health Organization WHO
- WHOQOL The World Health Organization Quality of Life

#### Chapter I

# Introduction

From being a hunter-gatherer to things being available at finger tips, human kind has come a long way. Rapid globalization has made the world increasingly interconnected and multifaceted, and technological advancements have made life much more convenient and fast paced. Along with urbanization economic development and modern work culture, there has been a rapid impact and change in the lifestyle of the people. This has undoubtedly put more strain on the global health especially in developing countries. Likewise the concept of health is being understood as the cumulative outcome of the influence of environment, socio-cultural, economic and institutional determinants (Martens, McMichael, & Patz, 2000). While the standards of living have increased, and access to services have improved, there has been significant impact on health of individuals in terms of faulty dietary patterns, and sedentary lifestyle- owing to energy saving equipment to do household chores, better transport facilities, lack of physically demanding tasks at work place and an absence of leisure activities (Chopra, Galbraith, & Darnton-Hill, 2002; Mohan, 2004). This has given way to the global epidemic of chronic illness (WHO, 2003). Often referred to as "non-life-threatening", lifestyle-related conditions (non-communicable diseases) such as cancer, diabetes mellitus, obesity, cardiovascular diseases, muscular-and-skeletal related problems and mental illness (Davies & Macdowall, 2006). As rightly put by Dreaper (2012) that in this era of modern civilization, people live longer, however with relatively high levels of sickness. They are becoming an important cause of disability, and premature death both in developed and developing countries (Steyn & Damasceno, 2006; David, et al., 2011; Molinaro, 2011)

and considered as a global threat upon individual's well-being and socio-economic activity (World Economic Forum, 2012). Reportedly 68% of the total global deaths (WHO, 2015) and 60% out of the total deaths in India were accounted due to different chronic illness (WHO, 2014). For instance in India, 20% of the population has at least one chronic illness and more than 10% of the population has more than one condition (Patel et al., 2011). Around 33% of deaths due to non-communicable diseases in India are among individuals below the age of 60 (David & Elizabeth, 2012). Among the various chronic illnesses, hypertension and diabetes have become epidemic diseases in India. This picture represents fundamental shortcomings in the way we address such chronic illnesses.

# **Diabetes Prevalence**

According to International Diabetes Federation (2013), diabetes mellitus is the fourth leading cause of death and for every six seconds a person dies from diabetes related complications. This non-communicable disease has been growing at an epidemic proportion (Bruno & Landi, 2011; IDF, 2012), with 422 million people suffering with diabetes around the globe and is expected to rise to 592 million by the year 2035 (IDF, 2014). Specifically Type II diabetes is on rise in every country with 77% of diabetes patients living in low-and-middle- income group countries with most number of people within the age range of 40-59 (IDF, 2014). The facts show that around 80 million people suffer from diabetes in India (WHO, 2014; IDF, 2014). In addition to this, Indian migrants across the world tend to have higher chances of suffering from metabolic disorders and developing Type II diabetes (Joshi, 2003; Deepa, Sandeep, & Mohan, 2006; Mohan, Sandeep, Deepa, Shah, & Varghese, 2007; Heikes, Eddy, Arondekar, &

Schlessinger, 2008; Grant, Moore, & Florez, 2009). The first phase of research conducted by Indian Council of Medical Research- India-Diabetes (ICMR-INDIAB)(Anjana et al., 2011) shows that the prevalence of diabetes in India has doubled from being 31.7 million in 2000 to 62.4 million in 2011. The study was conducted in three States and one Union Territory, and the results show the alarming rate at which diabetes is increasing. The prevalence of diabetes was found to be 10.4%, in Maharashtra it was 8.4 percent, in Jharkhand it was 5.3 percent and Chandigarh was found to be the highest with 13.6 percent of the population suffering from diabetes. And those at risk for diabetes or having pre-diabetes in these States were found to be 77.2 million. A study called the Sanofi SITE- 'Screening India's Twin Epidemic' conducted by Aventis Pharma Limited, the Sanofi Group, in three major cities of Andhra Pradesh found that 63 percent of the surveyed population suffered from hypertension, diabetes or both (Joshi, Vadivale, Dalal, & Das, 2011). From being an epidemic, diabetes has become a major public health issue which poses economic strain. The annual cost of diabetes in India was nearly 38 billion in the year 2011 (Tharkar, Devarajan, Kumpatla, & Viswanathan, 2010; Jha, 2013).

# Diabetes

Diabetes mellitus is a chronic metabolic disorder. The presence of high glucose level in the blood, known as hyperglycemia, characterizes diabetes. Hyperglycemia is caused due to relative or absolute insulin deficiency. This occurs when glucose, which is produced by the metabolism of ingested food, remains in the blood stream, without being absorbed by the cells in the body. Right after a meal, the glucose levels in the blood rise, prompting the organ pancreas to secrete the hormone called insulin. Along with the receptors in the cells, insulin helps glucose to enter cells, in order to be absorbed and stored in the form of fatty acids and amino acids. The absorbed glucose is essential source of energy for the human body to function and typically the brain's only source of energy. In people with diabetes, the pancreas is either unable to produce enough of insulin or the cells are unable to use insulin efficiently or both. When this happens, the cells are unable to absorb glucose for energy and the metabolized glucose remains in the blood stream leading to hyperglycemia.

## Diagnosis

The blood glucose levels are measured in terms of milligram per deciliter (mg/dl) or as millimole per liter (mmol/l) with specific numbers. The fasting (pre-prandial) blood glucose level in those without diabetes is observed to be less than 110mg/dl and is less than 140mg/dl two hours after consuming breakfast (post-prandial). Diabetes is diagnosed on the basis of the fasting blood glucose test. If the fasting plasma glucose level is more than 126mg/dl, tested on two separate occasions, it indicates diabetes (ADA, 2000), and if the post-meal plasma glucose level is above 140mg/dl, it further attests that the person is suffering from diabetes. If the fasting blood glucose remains above 100 mg/dl, but within the range of 100-126mg/dl, the condition is termed as impaired fasting glucose (IFG) or impaired glucose metabolism (Shaw, Zimmet, McCarty, & de Courten, 2000). A random blood glucose test can also be done to diagnose diabetes and is indicated when the blood glucose level is 200 mg/dl or higher. A common and important laboratory test called the glycosylated hemoglobin (hemoglobin A1c or HbA1c) is used to measure the glycemic control for the last 2-3 months. The recommended hemoglobin A1c goal is to be less than 7 % which implies that glucose levels are well within the good control range and action is suggested if is greater than 8%.

# **Types of Diabetes**

According to American Diabetes Association (2012), there are three main types of diabetes: Type 1 diabetes, Type II diabetes and gestational diabetes. Type 1 diabetes was previously referred as 'insulin-dependent' or 'juvenile-onset' diabetes, and Type II diabetes was referred as 'non-insulin-dependent' or 'adult-onset' diabetes.

In Type 1 diabetes, the function of the insulin-producing beta cells of the pancreas is hampered due to the auto-immune reaction. This leads to minimal or no insulin production, necessitating the person to daily administer injections of insulin to keep the blood glucose under control. This condition occurs in people of any age, but usually in children and before the age of 30. The symptoms in this condition appear abruptly. The classic symptoms being polydipsia(excessive thirst), *polyphagia* (excessive hunger), and *polyuria* (excessive urination). Symptoms may also include sudden weight loss, blurred vision, extreme fatigue, and delayed wound healing. About 5-10% of the diabetes population suffers from Type 1 diabetes. Treatment for Type 1 diabetes necessitates daily insulin therapy, close monitoring of blood glucose levels, healthy diet and regular exercise.

Type II diabetes is the most common type of diabetes, in which the pancreas either produces insufficient insulin, or the body is unable to use the produced insulin efficiently, also known as *insulin resistance*. Insulin resistance plays an important role in this type of diabetes , as the body lacks insulin or is unable to metabolize the available insulin, leading to higher than normal blood glucose levels or *hyperglycemia*. About 90-95% of the diabetes population suffers from this condition. It usually occurs in adults above the age of 40, however it been increasingly seen in people below the age of 35 and in children (WHO, 2003). Type II diabetes goes undiagnosed for a long time as the symptoms occur gradually. Symptoms usually include increased urination, excessive thirst and hunger, dehydration, weight loss, fatigue, lethargy, frequent infections, blurred vision and can even lead to coma, if the symptoms are ignored and treatment not administered. There are several risk factors for developing Type II diabetes which include obesity, physical inactivity, poor diet, family history of diabetes, and advancing age. Currently, Type II diabetes is growing at an epidemic rate, owing to increasing urbanization, ageing population, rapid economic development, and changes in lifestyle patterns. Type II diabetes affects more women than men and carries the risk of cardiovascular damage and doubles the risk of cancer of the pancreas (Huxley, Ansary-Moghaddam, de Gonzalez, Barzi & Woodward, 2005).

Gestational diabetes, which is the third type of diabetes, occurs in women who develop insulin resistance around the 24<sup>th</sup> week into pregnancy. This is caused when the action of insulin is blocked due to the hormonal changes during pregnancy. Gestational diabetes is not so much harmful to the unborn baby as Type 1 and Type 2 diabetes. However, uncontrolled or poorly managed blood glucose levels during pregnancy can lead to heavier birth weight of the baby (fetal macrosomia) which leads to prolonged obstructed labour and normal birth difficult and risky. Gestational diabetes usually disappears after baby's birth, however mothers have pose a greater risk of developing gestational diabetes in subsequent pregnancies or developing Type II diabetes later in life. Pregnant women suffering from gestational diabetes need to monitor and control their blood glucose levels in order to minimize risk to their unborn child by following exercise regimen, healthy diet pattern and adhering to medication regimen.

#### **Diabetes Complications**

Diabetes being a lifelong disease, poses a risk of developing microvascular, macrovascular and neuropathic complications. These serious health problems usually develop after having diabetes for many years and also due to consistently high blood glucose levels. As the prevalence of diabetes increases, so does the cost- in terms of both human and economic increases due to developing these life threatening complications.

The damage to small blood vessels in the eye (retinopathy) and kidney (nephropathy) is termed as *microvascular complications*. Damage caused due to bleeding or hemorrhage of blood vessels in the eye may result in loss of vision if not treated. The function of the kidneys is affected due to damage to the filtering units (glomeruli) leading to the accumulation of waste products in the blood. This may in turn lead to kidney failure, necessitating dialysis or kidney transplant.

The damage to larger blood vessels of the body is referred to as *macrovascular complications*. There are three major types of macrovascular disease: coronary artery disease, cerebral artery disease (cerebro-vascular), and peripheral vascular disease. The most common cause of death and complication in people with diabetes is cardiovascular disease which includes angina, stroke, myocardial infarction, and congestive heart failure (Graham, et al., 2010). The presence of high blood pressure, high cholesterol levels, increases the risk of macrovascular complications.

*Neuropathic complications* are nerve problems that involve multiple nerves and complications are chronic and progressive in nature. The symptoms increase with severity and duration of disease. This type of nerve problems occur in most of the diabetic patients. This affects sensory nerves leading to numbness, tingling or loss of sensation of the hands and lower extremities, foot ulcers or even amputation. It also affects involuntary bodily functions such as sexual dysfunction, incontinence, lack of sweating to name a few.

Diabetes patients also face a risk of poor oral health that includes inflammation of the gums (gingivitis), and tooth loss. Forty percent of people suffering from sleep apnea have diabetes (Meslier, et al., 2003).

### The Impact of Diabetes in Daily Life

Diabetes is not just an epidemic or public health burden but on a personal level it represents a daily challenge for those who are living with this condition and to their families. The challenge is a lifelong one, with no respite or cure available. Diabetes can be demanding, and all-consuming. Millions of people live with this condition, and for many it is a manageable and controllable condition, but for some it is associated with psychological burden and can lead to diabetes-related distress and burnout. Diabetes not just affects the physiology of the person but impacts all aspects of one's life.

# **Psychological Aspect**

To be diagnosed with diabetes itself, poses to be a traumatic event. Initially the person may feel relieved as he/she receives an answer to all the unexplained symptoms. However, individuals and their families go through a process of grieving. They may face anxiety, fear, denial, anger, bargaining, depression and finally acceptance (Bowes, Lowes, Warner, & Gregory, 2009). Coping during each of these stages is crucial for coming in terms with the diagnosis and influences their ability to make necessary changes to their lifestyle, and adapt to self-care routine.

# **Behavioral Aspect**

Right after diagnosis, patients feel overwhelmed by the amount of information they need absorb and what changes they need to implement to maintain glycemic control. It is challenging for every patient to bring about a change in prior lifestyle, adjusting to new therapy regimen, integrating new skills and activities into an already established daily routine appears to be difficult and distressing (Rubin & Peyrot, 2001). The unending daily self-management regimen requires great perseverance in order to achieve optimal health and reduce the risk of long-term complications. Therefore an individual's quality of life is compromised not only due to the condition but also by the therapy required to manage it (Rubin, 2000). The quality of life of the family members gets affected too, because of the anxiety associated with living with someone suffering from diabetes (Barnard, Speight, & Skinner, 2008).

#### **Social Aspect**

Suffering from diabetes has the potential of setting people aside from "normal" society and outside the norm of being healthy. Those with diabetes often report the stigma attached with the condition, thereby affect not just their health but social functioning (Barnard & Lloyd, 2011). Individuals feel pressurized to give up their dietary regimen in social setting, may forget to take their daily medication.

In addition, the knowledge that one's ability to achieve good glycemic control is directly related to decreased risk of developing complications leads to feelings of stress and exacerbates the difficulty of the task. Also many individuals feel unable to cope with their condition and research suggests that such people might be experiencing diabetes related distress or feeling overwhelmed and frustrated with the burden of diabetes self-care (Wardian & Sun, 2014). These emotions though different from being depressed, can be very destructive and discouraging in diabetes self-care.

#### **Diabetes Treatment and Management**

As reviewed by the American Diabetes Association (ADA, 2000) the treatment for Type II diabetes includes medical nutrition therapy; self-monitoring of blood glucose levels; adequate physical activity; insulin regimens and oral glucose-lowering agents when needed; regular medical care to modify treatment; and screening for complications. However, since diabetes is a chronic condition which cannot be cured but effectively managed. The corner stone of diabetes management is *self-management* which is a "set of skilled behaviors engaged to manage one's own illness" (Goodall & Halford, 1991). According to the Standards of Medical Care for Patients with Diabetes Mellitus (ADA, 2000), education for diabetes self-management is a vital component of overall management and emphasizes the need to address the individual's role in executing selfcare at initial and ongoing visits.

Adhering to the *pharmacological treatment* (oral glucose-lowering agent or administering insulin) as prescribed by the physician is the primary method of lowering and maintaining the blood glucose level within an acceptable range. However apart from the medication, *dietary principles* required for managing diabetes must be understood by

the patient and previous eating patterns must be modified. Medical practitioners insist patients on developing regular *exercise regimen* to assist in maintaining good glycemic control and achieving the desired weight. Another vital component of diabetes management is *self-monitoring of blood glucose* level and modifying the daily selfmanagement. Daily or periodic monitoring of blood glucose level should be encouraged. Finally, *stress management* affects the total diabetes management, as acute or chronic stress distracts the patients from attending to their usual self-care regimen, like forgetting to take medication, overeating or skipping a meal or neglecting exercise. Instead, patients tend to concentrate of managing their stress and this can lead to poor glycemic control, and extreme neglect can even lead to ketoacidosis requiring hospitalization (Katon, et al., 2005).

To avoid and delay the onset of complications diabetes patients are recommended to maintain optimal levels of glucose (Mohan, Venkatraman, & Pradeepa, 2010). In order achieve and maintain such control, lifestyle modification and adherence to medication are instrumental in bringing about healthy and sustained behavioral change among the patients.

The study focuses on the role of psychosocial factors in illness management referring to adherence and quality of life. Psychosocial factors refer to the understanding that illness and its symptoms, which vary from person to person and within the person at different periods of time can be attributed and explained by a combination of psychological, social and cultural factors. Out of the several psychosocial factors, the study included social support, knowledge of illness, and self-efficacy. One of the barriers in maintaining good glycemic control is lack of knowledge concerning the different aspects of the disease.

## **Knowledge of Diabetes**

According to Merriam-Webster's Online Dictionary (2015), the full definition of knowledge is "the fact or condition of knowing something with familiarity gained through experience or association". Knowledge of any illness includes the range of information an individual possesses concerning the condition. Knowledge of illness essentially consists of four aspects namely—symptoms, causes, complications, and treatment or management. Knowledge of these aspects equips the patient in effectively coping with the illness. However, diabetes patients across various socio-economic and cultural backgrounds have marked lack of knowledge on various aspects of the illness including self-care activities. Despite being the diabetes capital of the world, diabetic patients in India lack adequate knowledge about the illness (Hawal, Kambar, Patil, & Hiremath, 2013).

#### Sources of acquiring diabetes related knowledge

Considering the dearth of avenues providing health information in India, the main source of acquiring health related information for general population is from family, friends, relatives, and through media such as newspapers, magazines, television and radio (Kulkarni et al., 2012). In addition to these sources, diabetes patients receive information related to diabetes from their physician, diabetologist, health care staff, magazines, or booklets (Al-Mahrooqi et al., 2013). Other factors such as family history of diabetes (Azinge, 2013), having higher educational level and higher level of income also influences knowledge related to diabetes (Al Shafaee et al., 2008).

#### Impact of knowledge of diabetes on diabetes self-care

Acquiring the necessary information about diabetes aides a person in assessing their vulnerability to the consequences of the condition, seek the required medical care and treatment, motivate themselves to care and cope with the condition (Alele, 2014). Knowledge of diabetes is shown to increase self-efficacy (Atak, Gurkan, & Kose, 2008) in performing self-care behaviors (McEwen et al., 2007). Acquiring knowledge helps to make better health choices and adhere to treatment recommendations (Pongmesa et al., 2009) such as regular exercise, balanced diet, regular blood glucose monitoring (Murata et al., 2003) adherence to medication leading to better glycemic control (Al-Qazaz et al., 2011). Possessing knowledge not only helps in making better health choices but improves quality of life of the patients, increases healthy coping (Siminerio, Ruppert, Huder, & Toledo, 2014) and reduces diabetes related distress (Fisher, Hessler, & Glasgow, 2013).

Providing diabetes education aimed at increasing patient's knowledge of diabetes not just increases positive self-care activities but also decreases psychological distress and improves their coping strategies. This kind of information can also be acquired through appraisal support offered by organizing workshops in clinics, awareness programs for masses and also by the patients' social network which includes family, friends and health care professionals.

It is at this juncture that the role of health care professionals becomes prominent. The rapport between the patient and health care team is an important one, as the patient needs to be educated about necessary information about the condition, the importance of learning new self-care tasks must be told, and apprehensions about future health and possible risk complications must be discussed. Most often than not, health care professionals tend to focus more on medical outcomes, good glycemic control, and minimizing the risks, but the person with diabetes may be more concerned with how he can continue his daily activities and also manage diabetes care at the same time. Health care professionals, especially the primary care providers, physicians must be empathetic towards the patients and understand the psychosocial adjustments and difficulties that the patients need to make, along with their biomedical needs. This is also important as individuals may have the same level of physical health but can differ in their levels of well-being and functioning. Optimal level of functioning and well-being depends on variables such as psychological factors, family and social support, available material resources, educational and cultural background. The support from medical care providers and social support from family and friends becomes essential as the newly diagnosed patient would still be grappling with their status if being a "diabetic" and support and information is welcomed as they try to learn self-management. This helps in healthy adjustment of the patient, because the daily burden of diabetes takes a toll emotionally and psychologically, appropriate medical and social support helps them to put their disease into context, make it as a part of their life, instead of feeling 'controlled' or 'burdened' by it, and brings a healthy balance and good quality of life (Lustman, et al., 2000; Schram, Baan, & Pouwer, 2009). The support received from medical care providers, social support from family and friends is considered to be helpful for patients

in sustaining healthy lifestyle changes and adhering to treatment (Gleeson-Kreig, Bernal, & Woolley, 2002).

# **Social Support**

The construct of social support has been defined in myriad ways by different researchers. According to Cassel (1974), social support consists of feedback conveyed in signs and signals from primary group members that correct deviations at the behavioral, cognitive and emotional levels. Caplan (1974) defines support systems as social interactions with another individual, a network, a group, or an organization that provide individuals with opportunities for feedback about themselves and for validations about others. Cobb (1976) views social support as information that leads the individual to believe that one is cared for and loved and that he/she is esteemed and valued, that he/she belongs to a network of communication and mutual obligation from social networks such as family (parents or spouse), relatives, friends (Rietschlin, 1998), social communities such as coworkers, religious groups or clubs or even a devoted pet (Allen, 2003). House (1981) gave an explicit definition of social support and outlined four broad classes or types of behavior as potential forms of social support: emotional support, instrumental support, informational support, and appraisal support. Social support can also be defined as "an exchange of resources between (at least) two persons, aimed at increasing the well-being of the receiver (Shumaker & Brownell, 1984). Gottlieb (2000) defines social support on similar lines, as a process that involves interaction among interpersonal relationships which help in improving coping, self-esteem, belonging and competence through actual or perceived exchange of psychosocial or physical resources. According to Uchino (2004), social support refers to the comfort, care, esteem, or assistance available to the individual from other people or groups. Few social relations provide supportive functions merely because of their existence. Social support is considered as an essential source of life satisfaction and emotional well-being (Reis & Gable, 2002; Seligman, 2003). Support enables individuals to enjoy and cherish life and helps them cope with strenuous and stressful situations acting as a buffer against traumatic life events (Diener & Seligman, 2004). The quantity and quality of support is associated with reduced risk of poor mental and physical health and mortality (Reblin & Uchino, 2008). Individual who receive psychological and material support from family and friends when in need, are found to be happier and in better health than those who are socially less connected (Lyubomirsky, King & Diener, 2005).

# Theories

Researchers have proposed two theories to elucidate how social support influences health: the buffering and the direct effects or (main effects) hypotheses (Cutrona & Gardener, 2004; Wills & Fegan, 2001).

According to the buffering hypothesis, social support leads to better health by protecting or shielding the person against the negative impact of high stress (Cohen & Wills, 1985). This protective function is effective mainly or only during times of strong stressor. However, during the times of no stress or minimal stress, the buffering effect does not occur (Karlin, Brondolo, & Schwartz, 2003). The buffering effects may occur in two ways. First, during the times of severe or strong stressor, individuals who are having high levels of social support are more likely to appraise the situation as less stressful than those with low level of social support. And those with greater social support stay positive as they expect that they will receive help from their support group. Secondly, having high

level of social support may alter individual's response to the stressor after the initial appraisal. The support helps the individuals to view the stressor as less severe and manageable. Individuals with low levels of social support are less likely to have these advantages and therefore there is greater negative impact of the stressor on them.

On the other hand, the direct effects hypothesis emphasizes that, the beneficial influence of social support tends to be similar when the intensity of the stressor is either high or low. This implies that support has an impact on individual's health and well-being, regardless of the amount of stress they experience. According to this hypothesis, people with high levels of social support, have regular social interaction and have a strong sense of belongingness and self-esteem (Cassel, 1976). This may have a positive influence on health independent of the stress. Social relationships influence individual's attitudes towards behaviors related to health. People with high levels of support tend to feel that their loved ones need and care about them and hence are motivated to engage in healthy lifestyles (Pierce et al., 2000).

# **Different Perspectives and Types of Social Support**

Social support can be understood in terms of *structural aspect* or *functional aspect* (Uchino, 2004). Structural aspect is the presence of interpersonal relationships and inter-connections between these social ties (e.g., marital status, number of relations or number of relations who know one another, group memberships). In other words, it is the quantity of social ties or *social network* that one has, and the frequency of contact among the network members (Friedman & Silver, 2007). And the function that these social ties serve is the functional aspect. It is the availability of resources provided by the existing interpersonal relationships to serve particular functions such as providing care and

affection, feelings of belonging or material aid. It is quality of the social relationships and the support they extend in the context of dealing with a stressor (Friedman & Silver, 2007).

Distinction can also be made in terms of perceived support and the actual support received i.e. received support (Uchino, 2004). Actual support can be referred to as support that can be objectively verified, for example, receiving financial support (Kaniasty, 2008). Perceived support is the subjective interpretation or the perception of individual, as to how much support is available to them and is highly related to positive outcomes. Distinction is also made between the expected support (what one expects) and received support and between event-specific support (support that meets the demand of the specific stressful event) and general support (constant presence of support across situations) (Dalgard, Bjork, & Thambs, 1995).

Though researchers differ in the way they categorize the types of social support, they usually agree upon the following types:

Instrumental or tangible support: It refers to providing tangible or concrete assistance in terms of financial aid, material resources or needed/ instrumental services (Sanderson, 2013). It can include a wide range of activities such as, taking care of children, lending or donating money, helping out with household chores, running errands, providing transportation, looking after the household while the owners are away and providing material goods such as furniture or tools (Uchino, 2004). Providing assistance with such kind of chores during physical illness or injury is a very important form of instrumental support as the person who is receiving help may be totally or partial unable to undertake the necessary tasks.

Informational or appraisal support: The term refers to the process of receiving information, advice and guidance from others. This includes providing information about the root cause of the problem, providing suggestions about one's decision, or information about organizations that provide help. It helps the individual in understanding or appraising the problem with a different perspective and find out which resources and coping strategies they need to use to deal with it (Friedman & Silver, 2007). This includes, giving advice on how to handle a personal or professional problem, giving information on management of the illness or guiding in seeking help or suggesting best medical care providers. This kind of support operates as a buffering process (Uchino, 2004). When environmental stressors such as illness, exceed the individual's knowledge or problem-solving skills, information, advice and guidance to new sources of information provides valuable assistance.

*Emotional support:* This kind of support refers to the expression of concern, care, warmth and empathy and providing love, reassurance, comfort, nurturance and encouragement to the person in a stressful state (Friedman & Silver, 2007). Individuals who face stressful events feel the need to share about the events and providing a 'listening ear' is greatly valued (Sanderson, 2013). Support helps the person to openly express and ventilate his/her feelings and beliefs. It helps in providing a sense of acceptance and provides constructive and positive direction to the individual. It has an influence on the affect of the person, because of the expression or information that a person is loved, cared for, and cherished.

**Belongingness support:** The support provided by social relationships is that of social companionship or belongingness where the individuals enjoy having the company

of others to engage in social activities such as going out for a dinner/ party, movie/ concert, or camping/ sports activities. Such kind of everyday pleasurable activities provide access to more instrumental and esteem support due to shared interests, reciprocity and closer relationships. This kind of belongingness or companionship is a major contributor to positive mood (Maestas, Vaquera, & Munoz Zehr, 2007).

*Esteem or validational support:* Receiving affirmation of self-worth or esteem is also beneficial to the individual. This type of social support gives the feedback/ validation to the individual that he or she is valued, cherished and respected, esteemed by others (Sanderson, 2013). It acknowledges or reinforces a person's beliefs, sense of self, and helps in positive interpretation of the situation and feelings. Events that bring up doubts about one's ability, social desirability, and career performance, pose a threat to one's self-esteem. Having a confidante – a person in whom one can confide, counters the negative effect on the self-concept. Events involving interpersonal conflict, which directly or indirectly involve criticism and devaluation by others, leads to ego-threat. Receiving acceptance and esteem from significant others serves as an antidote to an unresolved interpersonal conflict (Cohen & Syme, 1985).

Though there are many types of social support, the functions are beneficial to specific conditions or stressful events. Researchers have proposed the term *matching hypothesis* (Cohen & Wills, 1985; Cutrona & Russell, 1990), according to which the efficacy/ usefulness of any form of social support will depend on the extent to which the support meets the demands of the specific stressful event. For controllable events such having lost a job and finding a new one, needs informational or tangible support, as it directly addresses the need of the stressor. For uncontrollable or unpredicted events such

as losing a dear one, or betrayal in relationships, emotional or belongingness support helps in coping with the event. However, matching hypothesis has been criticized as many events do not clearly fall under the category of controllable or uncontrollable events (Barrera, 2000). For example, coping with a medical diagnosis may be difficult and uncontrollable in the beginning, but adapting and learning to manage the condition is controllable, and at different stages, different kind of support is needed. However, both emotional and informational support was found to be helpful across different situations and life events (Lindorff, 2005).

#### **Sources of Social Support**

Support is received from different types of social relationships, such as intimate/personal relationships (spouse, family, relatives, coworkers and friends), formal organizations that are not related to one's work (medical professionals, service/charity organizations, school boards, social clubs, religious/ cultural organizations), and social contacts from active leisure activities (attending classes like swimming, aerobics, gym). Sometimes social support is also sought for and obtained from peers going through the same condition/illness, called peer-support groups. This kind of help or action is sought out when social network of the person is inadequate or not equipped to meet the needs of the person. Peer support not only helps the person but also the support-giver, referred to as the helper-therapy principle (Helgeson &Gottlieb, 2000).

Social support influences health by either having a buffering effect or direct effect by reducing the impact of the stressor, and thereby minimizes the body's physiological response to the stressor. It also has an influence on individual's appraisal of the situation, coping strategies and helps them in adapting health-promoting behaviors. In the context of diabetes care and management, social support acts as one of the major psychosocial factor in enabling the patients to adjust and adhere to self-care activities. As mentioned earlier, patients diagnosed with diabetes experience psychosocial challenges and emotional distress as they try to manage their fluctuating glucose levels. As a result patients tend to experience low level of quality of life. Having social support is crucial for diabetes patients as they can receive support in the form of information, advice, knowledge, required materials, and emotional support that buffers them against "diabetes burnout" (Clark, 2008). Apart from the informational and appraisal support, emotional support helps in promoting feelings of comfort and modifies the perceived stress and physical reaction that the patients experience enhancing their quality of life. Strong social relationships, educational qualification, job opportunities, interpersonal moderators and barriers significantly affect the quality of life of individuals with chronic conditions. Social support also helps in developing suitable coping strategies to deal with stress of having the illness and bringing about a structure to daily routine and reduce the likelihood of poor health by following the treatment regimen (Kadirvelu, Sadasivan, & Ng, 2012). Research shows an increased adherence to diet, exercise, and glucose testing in the presence of perceived social support. However, the role of social support was found to be unclear as there was no relationship between actual glucose control and support (Wilson et al., 1986). Adopting healthy lifestyle and brining about behavioral changes to manage diabetes helps in achieving optimum glycemic control, and minimize or prevent diabetes related complications (Sousa, Zauszniewski, Musil, Price Lea, & Davis, 2005). These behavioral changes are complex and are influenced by factors such as beliefs, skills, knowledge, social support and motivation. This need to achieve behavioral goals points

out to the role of self-efficacy which is another psychosocial factor that influences the diabetes adherence. Research also shows that greater self-efficacy regarding the diabetes regimen led to greater adherence and better glucose control and eventually enhances one's quality of life (Johnston-Brooks, Lewis, & Garg, 2002).

# **Self-efficacy**

One of the powerful predictor of whether an individual actually engages in a certain behavior is self-efficacy. The Social Cognitive theory (Bandura, 1986) includes the role of the individual's self-efficacy in order to achieve a goal. Self-efficacy can be defined as the perceived ability or belief in one's capabilities to organize and execute specific behaviors necessary to achieve one's goals and to manage one's prospective situations (Bandura, 1986, 1997). O'Leary (1985) was one of the first few to emphasize applying the concept of self-efficacy in the performance health behaviors and adherence. According to O'Leary, self-efficacy predicts better adherence than that of personal locus of control or instilled fear.

According to Bandura (1998), self-efficacy beliefs influence health in two distinct ways. Firstly, individual's possessing greater sense of self-efficacy to initiate certain health behaviors or reach some goals are likely to put forth greater effort to perform the behaviors. Such individuals possess greater confidence and motivation to maintain these changes and sustain them even if they face occasional setbacks. For example, a person who has high confidence in his ability to develop an exercise regimen tries harder to maintain it even if he happens to skip a day or two without perform his daily exercise routine. However, a person with low self-confidence in performing such activity may put in little effort and may give up easily when faced with a setback. Secondly, self-efficacy plays a role in physical health by influencing the physiological pathways which are involved in the relationship between stress and illness. Individuals with low self-efficacy have higher physiological response to stressful situations like being diagnosed with chronic illness or having to change one's diet pattern. They tend to have higher heart rate, shallow breathing, and higher blood pressure than those with higher self-efficacy. This sort of anxious response to making a change may discourage those with low-self-efficacy to even attempt to initiate the behavioral change. In contrast, an individual's belief that they are capable of performing a future action reduces their anxiety and has an impact on their cognition and emotions to set high personal goals. Succeeding in achieving such a goal acts as a feedback loop in increasing sense of self-efficacy.

The perceived self-efficacy that an individual possesses has greater impact on behavioral changes related to health than one's true abilities. Perceived self-efficacy affects behavior in various ways: (1) the execution or non-execution of a behavior (the decision to attempt or avoid a behavior based on the perceived ability to execute the task) (2) the extent to which they can put in their effort (3) the extent to which they can persist in that behavior and (4) the resultant emotional reaction if the person fails in that behavior (coping). Individuals possess varying level of perceived self-efficacy for different tasks (Bandura, 1977).

According to Bandura (1997a), self-efficacy can be improved in four ways: mastery experiences, modelling, verbal persuasion and social evaluation, and by interpreting one's physiological state and emotional experiences.

# Ways to Improve Self-efficacy

# Mastery Experiences

In the course of diabetes self-care, one needs to estimate their ability to carry out a task, understand the nature of the task and potential barriers, and have a clear idea and definition of success in that particular task. One of the most challenging tasks in diabetes self-care is goal-setting and problem-solving as patients tend to set unrealistic goals which are beyond their ability and skill. For example, patients may set high goals and to lose weight in short period of time or may want to alter their lifestyle without proper planning. Mastery experiences are also called as 'guided mastery' as they involve planning of appropriate behavioral challenges accompanied with guidance and support. Through guided mastery individuals can effectively learn and develop health behaviors such as diet and exercise regimen by setting small goals and achieving them through practice. This learning cycle through guided mastery eventually helps in improving one's self-efficacy (Ott et al., 2000). When an individual does not possess the necessary selfefficacy for certain behavior, setting an unrealistic goal which may eventually lead to a failure has a greater negative impact on their motivation. This points out to the importance of guided mastery to bring about behavioral change along with having enough of support to sustain the change.

# Modelling

Another way in which one's self-efficacy can be improved is through vicarious learning or modelling. This involves observing another person (model) performing the target behavior successfully and learning from their experience (Holmes et al., 2006). Also called as observational learning, new behaviors can be learnt through observing others (model) perform it. This involves four processes of attention, retention, behavioral production and motivational processes. Firstly, the person needs to attend to the behavior being performed and carefully retain the information by transforming discrete ideas into well organized and general principles which can be applied in different situations. Behavioral production involves translating into behavior all the information that was attended to and retained. At this stage, the capability of the individual and skill required to execute the behavior determines how well they can perform the modeled behavior. After repeated performance of the modeled behavior and evaluation of the same in comparison to the observed behavior, individuals can modify it to improve. Finally, the motivation influences the outcome of the modeling on the self-efficacy of the individual. The most important aspect of the process of modeling is setting a moderate and achievable standard of performance which can boost their self-efficacy. However, individuals who are highly motivated to achieve a high level of performance may face low levels of self-efficacy if their performance does not reach up to the standard of the model that they have observed.

### Verbal Persuasion and Social Evaluation

Verbal persuasion is the impact that a person has on the individual by providing the necessary information. However, the extent of impact that the informant has on the individual is determined by the confidence vested in the informant (Mulvaney et al., 2008). Therefore, appropriate information or feedback from a reliable source can have a significant impact on behavior change efforts. Positive feedback given by a reliable source which is realistic, focuses on the progress that is achieved, highlighting the personal capabilities of the person, helps motivates a person to try harder and persist in the behavior. Feedback needs to be positive in terms of how close the person is to reach the goal-competence gained, rather how much one is deficit in reaching the desired goalcompetence deficit. Social evaluation plays an important role as undermining one's efficacy through deficit oriented feedback is easier than to boost their efficacy through positive feedback (Bandura, 1997).

### Physiological and Emotional State

The individuals' interpretation of their physiological responses or emotional experiences also has an impact on their self-efficacy. Individuals tend to expect failure if they are physiologically highly aroused. This occurs as a result of past occurrences of physiological arousal with impaired performance. However, the impact of physiological arousal is determined by the interpretation of the individuals. For example, interpreting increased heart rate, sweaty palms before performing a task as excitement, and heightened interest rather than as a sign of incompetence or versus fear, may lead to an energetic performance rather than an impaired one (Ott et al., 2000). In addition to the interpretation of subjective physiological responses, affective states of the individuals also impact their self-efficacy. Positive mood contributes increased sense of efficacy as individuals tend to recollect and focus on past success and strengths. Whereas negative mood leads to lowered sense of efficacy as they focus of past failures and weaknesses.

Apart from these four factors that can improve one's self-efficacy, individuals need to possess the necessary knowledge and skill to perform the required behaviors and appropriate incentives to sustain the behavior (Rimal, 2000).

In the context of diabetes management and self-care, the concept of self-efficacy can be understood as the patient's conviction in his/her ability to bring about lifestyle changes to perform various health promoting behaviors on a daily basis and sustain these changes over a long period of time. For example, among diabetic patients, individuals who believe that they will be able to follow through their intentions of maintaining proper diet, exercise regularly and adhere to medications will be more likely to carry out the behavior than those who doubt their ability to carry out such health behaviors. Improving patient's self-efficacy is an important facilitator of adherence to diabetes self-care and treatment regimen which helps in reducing diabetes related mortality and delays or reduces the risk of developing diabetes-related complications (Schechter & Walker, 2002). Also, having greater self-efficacy gives individuals a sense of confidence and control over their health, and overall well-being leading to improved quality of life.

### Adherence

Adherence to treatment can be defined as a person's willingness and ability to follow health practices recommended by the health professionals. The combined definitions given by Haynes (1979) and Rand (1993) provide a broader understanding of the term as – the extent to which an individual's behavior of taking medication, following a diet, and executing lifestyle changes, coincides with the recommendations made by a health care provider. Adherence and non-adherence are not seen as the extreme ends of the continuum rather, it exists on the continuum from total adherence, through different levels of partial adherence, to not adhering at all (Aslani & Pasquier, 2002). The *form* and *intentionality* of non-adherence may differ. For instance, consuming excess dosage of medication than prescribed is considered as a form of non-adherence. The degree of intentionality with reference to non-adherence may differ from patient to patient. Few patients who understand the physician's recommendations may modify the regimen or

choose to ignore it as they are unwilling to follow them. This is called intentional nonadherence (Mo & Mak, 2009). However, in the case of unintentional non-adherence, individuals who intend to comply but due to some reasons are unable to do so (forgetting). The term adherence also differs from compliance. Compliance refers to reluctant obedience or conformity of patient's behavior to the orders of physicians. In contrast, adherence indicates a willing agreement on the part of the patient to comply with the recommendations of the physician without being ordered or forced to do so. Hence adherence is a conscious choice of the patient, where one may comply in a situation and may not in another. Adherence behavior can be understood in depth through different models and theories. The important models which are jointly referred to as social cognition models are: health belief model (HBM; Strecher, Champion, Rosenstock, 1997), theory of planned behavior (TPB; Ajzen & Fishbein, 2005), self-regulation model (SRM; Leventhal et al., 1998) and theory of self-efficacy (Bandura, 1986).

#### **Theories of Adherence**

# Health Belief Model (HBM)

According to the HBM, adherence is practiced as a result of the individuals' analysis of cost-benefit of the behavior. The model suggests four beliefs that contribute to one's adherence behavior: benefits of adherence (such as reduced symptoms, better glycemic control); possible barriers to adherence (such as financial costs, side effects of medication); apparent vulnerability to the illness (susceptibility or extent of developing disease related complications) and apparent severity of the outcome of the illness (perceived severity of the impending complication). Increased adherence is observed when the individuals perceive greater vulnerability to illness, high severity of the consequences of the illness, greater perception of the treatment benefits, and lesser barriers to adherence. In addition, these health beliefs are influenced by factors such as the individual's previous experiences, their personality and opinion of others.

# Theory of Planned Behavior (TPB)

The basic premise of the TPB is that the behavior of individuals could be predicted by their intentions. The individuals' attitude towards a particular behavior, his/her subjective norm with regards to the behavior, and their perceived ability to perform the behavior, determines their intention to actually perform the behavior. This process can be termed as behavior control. The TPB assumes that the individual's intention to behave in particular manner is directly related to the beliefs they hold about engaging in that behavior. However, it is uncertain of these beliefs are accurate; they may be irrational or biased. According to this theory, once these beliefs are formed, attitudes specific to the behaviors are formed according to evaluation of social norms of the behavior, and perceived ability to perform the behavior. The formation of attitudes regarding a behavior leads to intentions of actually engaging in that behavior.

# Self-regulation Model (SRM)

According to this model, the patient's response to the illness is based on their knowledge, perceptions and evaluation of the illness. Fundamental to the process of responding to the illness is to recognize that illness (the experience of being unwell) differs from disease (being diagnosed with pathology). Illness, which is a subjective experience may or may not be associated with the physical pathology (disease). When an individual faces a health threat, he/she tends to construct a personal representation of the illness. These illness representations are the patient's own beliefs about the illness. This

representation of the illness at the cognitive level is accompanied with the generation of the emotional responses, which together determine their response to the illness.

Apart from the above mentioned theories, self-efficacy theory (Bandura, 1986, 1997, 2001) and trans-theoretical model (Prochaska, Norcross, & DiClemente, 1994) also provide an understanding of adherence.

# Social Cognitive Theory

According to this theory, human action is influenced by an interaction of behavior, environment, and individual factors- mainly cognition. Bandura (1986, 2001) referred to this triad as reciprocal determinism. Another important factor that influences adherence is self-efficacy, which is situation specific and not a global concept. A combination of both self-efficacy and outcome expectancy play a vital role in predicting behavior.

# Trans-theoretical Model

Another theory that provides an understanding of adherence behavior is the transtheoretical model. According to this theory, individuals progress or regress through the five stages in the process of making changes in behavior. These five stages are precontemplation, contemplation, preparation, action and maintenance. In the precontemplation stage, an individual does not have any intention of altering their behavior. In contemplation stage, there is an awareness of the problem and making a change in behavior is at the thought level. In the preparation stage, there are both thoughts to change the behavior and preparation or gathering the resources and planning the course of action take place. During the action stage, the individual engages in overt behavior that represents the change they intend to make. Finally, in the maintenance stage, the individual makes efforts to sustain the changes in the behavior and in preventing a relapse of the previous behavior. According to the theory, an individual moves from one stage to another in a spiral manner than linear. Therefore, it is expected that an individual may progress or regress the stages several times before making a complete change to their behavior. In each stage, people require different types of information and assistance.

If all the theories are taken into consideration it is noted that a number of psychological factors such as perceived benefits and costs of adherence perceived vulnerability and severity of the illness, individual's beliefs, attitudes, and their appraisal of other's beliefs, self-efficacy, and the process of bringing about the change in behavior, influence adherence to health-seeking and enhancing behaviors.

# **Factors Influencing Adherence**

Apart from the above psychosocial factors, four other major factors affect adherence to treatment. They are treatment characteristics, patient factors, clinician's personal characteristics, factors related to the clinician-patient interaction (McDonald, Garg, & Haynes, 2002). Other factors such as environmental and cultural factors also influence adherence.

# **Treatment Characteristics**

According to Kasl (1975) the nature and knowledge of the treatment regimen in itself predicts the likelihood of adherence. Complex treatment regimen and medication regimen leads to lower levels of adherence. This is increasingly noticed in chronic illnesses (DiMatteo, 2004). Increasing the dosage from one to two doses per day also has an impact on adherence. Simple medication regime shows enhanced short-term and longterm adherence in conditions like glaucoma (Robin et al., 2007), AIDS (Battaglioli-DeNero, 2007) and diabetes (Dailey, Kim, & Lian, 2001).

Negative side effects of the medication often lead to reduced patient adherence. This aspect of the treatment needs to be monitored and managed by the clinician. Side effects of the medication are usually considered to be a hindrance to adherence across chronic illnesses such as heart failure (Wu et al., 2008); and blood pressure (Elliott, 2008).

Accessibility in procuring the medication, such as having to travel to the pharmacy, consult the doctor and not having enough of finance to purchase the medication also acts as a barrier to adherence. In addition to this adherence is also affected when patients do not experience many symptoms (asymptomatic). The duration of disease also influences adherence, the longer the duration, lower is the level of adherence to treatment (Dailey, Kim, & Lian, 2001).

# **Patient Factors**

The demographic factors such as age and gender impact adherence behavior to a certain extent, though they are considered to be far too small and complex predictors of adherence (Dimatteo, 2004a). Largely, adherence tends to be lower among older patients than among younger patients in self-care activities such as insulin administration, exercise regimen, and blood glucose monitoring (Stetson et al., 2000). However, older adults experience problems such as complex treatment regimen, more number of medicines, lower cognitive abilities, decreased mobility and visual acuity, which lower their adherence behavior (Gans & McPhilips, 2003). Though there are few and

insignificant differences in adherence among men and women (Dimatteo, 2004b), women tend to follow healthier diet patterns and exercise regularly at home. However, both men and women tend to adhere to taking medication (Oman & King, 2000).

Emotional and personal factors play a role in adherence as well. Stressful life events tend to have a negative impact on adherence such as exercise regimen (Oman & King, 2000) and diet regimen (diet type and amount) (Karkashian, 2000). Individuals who have high generalized anxiety are usually hyper-vigilant and have low adherence whereas those having disease specific anxiety demonstrate better adherence. Extreme fear of self-administering insulin and self-monitoring of glucose levels leads to low adherence and emotional distress (Mollema et al., 2001). Depression plays a major role in failing to adhere with depressed patients being non-adherent three times more than non-depressed patients (Dimatteo, Lepper, & Croghan, 2000; Gonzalez et al., 2004). Depression often leads to complications and poor glycemic control among diabetics (DeGroot et al., 2001). Personal beliefs such as self-esteem and self-efficacy (Gans & McPhilips, 2003) play an important role in adherence. Individuals with high levels of self-esteem, show high adherence to physical activity, dental care and make adjustments to insulin doses (Kneckt et al., 2001). Similarly, individuals with high diabetes specific self-efficacy adhere to activities related to self-care (Plotnikoff, Brez, & Hotz, 2000). Belief in the effectiveness of the treatment and medication also has an impact on adherence (Ramstorm et al., 2006). Those who have poor understanding of the medication regime and poor insight into illness are more likely to be non- adherent (Iihara et al., 2004; Buckley et al., 2007).

Cognitive skills such as planning tasks, remembering to execute behaviors, and overcoming obstacles caused by intellectual disability, dementia and depression, increase

the likelihood of non-adherence to treatment (Wallace, Dyer, & Penrod, 2006). Patient motivation is an important factor in health behavior change (Rollnick, Mason, & Butler, 2000) and is directly related to adherence to treatment regime (Bisono et al., 2006). Other factors such as substance abuse is associated with poor medication adherence, diet and doctor's consultation (Janssen et al., 2006).

### **Clinician Factors**

Patients' adherence to treatment regimen may be influenced by the clinician, however not all clinicians consciously try to improve the adherence of patients (Petrilla et al., 2005). This may be due to factors such as clinicians' competence, resources and attitudes (Byrne et al., 2005). For example, not many clinicians hold positive or nonstigmatizing attitude towards their patients nor do they develop such attitudes. This hinders their ability to work effectively and make an impact on patients' adherence (Buchanan, Rohr, Stevak, & Sai, 2007).

According to Brawley and Culos-Reed (2000), self-efficacy is beliefs pertaining to specific areas of functioning and ability to use the possessed skills in a given situation. One of the ways to improve self-efficacy is through mastery experiences, and through the knowledge and skill training experience which can be provided by the clinician. However, if the clinician is not competent to deliver such knowledge, self-efficacy for a behavior may be low. Therefore attention to the competency and needs of the clinician is also as vital as focusing on the patient to improve adherence to treatment.

In addition, patients' perspective that clinician's tend to look down upon them, and that they treat them with disrespect are also likely to lower adherence to their advice and keeping their regular consultations (Blanchard & Lurie, 2004). The clinician's gender also plays a role in the nature of exchange between the clinician and the patient. Roter and Hall (2004) found that female clinicians tend to spend more time with their patients engaging in patient-centered talk, enquiring about their condition and forge a partnership with the patient, than the male clinicians. Patients also tend to share more with female clinicians more than male clinicians. This shows that female clinicians tend to establish the kind of relationship that leads to enhanced adherence.

### The Clinician-Patient Interaction

There is an increasing awareness that the nature of therapeutic relationship between the clinician and the patient has a great impact on the outcomes of the therapy (Kerse et al., 2004) and that forging a partnership enhances adherence (Sajatovic et al., 2005). This 'therapeutic alliance' involves the behavior, attitudes, and expectations of the clinician, which promote and sustain the alliance for the benefit of the patient. Skills used by the clinician during the consultation session such as having a structure or an agenda, addressing patient's resistance to treatment enhance the therapeutic alliance. Behaviors such as being indifferent to patient's concerns, overlooking their complaints, being inflexible, lacking a collaborative approach to the treatment and being coercive towards the patient lead to poor alliance (Ackerman & Hilsenroth, 2003).

Clinician's attributes such as the ability to communicate to the patient the level of competence he/she possesses, to be flexible, responsive and empathetic positively affect the therapeutic alliance (Ackerman & Hilsenroth, 2003). These attributes in clinician tend to encourage the patients to talk openly in return (Ciechanowski, Katon, Russo, & Walker, 2001). In addition, factors such as differences in native languages, ethnic background, socio-economic status, educational level, and using medical terminology

hinder communication between the clinician and the patient. As a consequence, patients do not understand or tend to forget the information given to them by their doctors (Blanchard & Lurie, 2004).

### Cultural and Environmental Factors

Cultural norms and beliefs have a significant effect on the extent of adherence. For instance if one's family or cultural tradition places strong belief in faith healers or tribal healers, the individual's adherence with modern medical treatment may be low. This is increasingly seen in those who immigrate and those who retain strong ties to their traditional healing methods (Barron, Hunter, Mayo, & Willoughby, 2004). Therefore those who believe in different healing tradition may not be strictly called as non-adherent even when their illness demands for a biomedical regimen. This may be partly because their cultural beliefs have a more holistic and spiritual approach and emphasize family support and cohesion. Another aspect of cultural factor hindering adherence is that clinicians tend to have negative and stereotypical attitude towards persons belonging to few ethnic groups such as African-Americans and low income groups. Such apparent discrimination and disregard is considered as a significant factor hindering adherence to clinician's recommendations and regular consultation (Blanchard & Lurie, 2004).

Two environmental factors hinder adherence specifically among diabetes patients. They are high-risk situations and the environmental systems. Self-care behaviors related to diabetes occur in the context of ever changing environment at home, work, social gatherings, etc., which come with their own demands and priorities. With every changing situation, patients are challenged to modify and adjust their self-care behaviors and choose between focusing on self-management or the priorities of life. Such situations are associated with low adherence and are called as "high-risk" situations (Schulndt, Sbrocco & Bell, 1989). Examples of such situations include: eating out or at social events, or difficulty to monitor food intake in accordance with social context, time of the day or place. Secondly, environmental factors include the political, economic, health care, ecological, agricultural and cultural systems around the individual. For example, changes in economic, agricultural and political systems have made available affordable fast foods high in salt, fat, and cholesterol content, have paved the way for better transport systems, and individuals spend more time in sedentary activities. Factors such as these hamper and reduce adherence to healthy self-care behaviors.

In addition to high risk situation and environmental systems, economic factors such as income, educational level and ethnicity of the individual have an impact on health status, adherence, and health care access (DiMatteo, 2004b). For example, individuals may take fewer or lower doses of medication in order to make their medications last longer, which compromises the effectiveness of the medicine. Also, the level of support one receives from family and friends also influences adherence. Those who lead isolated lifestyle have poor adherence when compared to those living with families and having close relationships with others (DiMatteo, 2004a). However, the type and function of the kind of support they receive is of paramount importance. For instance, though an individual lives with his/her family but has constant interpersonal conflict, acts as a negative factor for adherence.

Consequently, adherence behavior is influenced by various factors and not just by patient's factors. The ability to manage one's self-care is determined by intra-personal, inter-personal, environmental and cultural factors that interact in a complex fashion.

## **Strategies for Improving Adherence**

Strategies for improving adherence fall largely into three categories: psychoeducational approach, behavioral strategies, and cognitive-behavioral interventions.

### **Psycho-educational Approaches**

Enhancing patient knowledge about treatment regime and medication use plays a vital role in improving adherence, predominantly when patients hold negative beliefs about treatment (Fernandez et al., 2006). Knowledge helps the patient to gain an insight about the interplay of symptoms, illness, treatment, recovery and therefore increases motivation to adhere to the treatment regime. Psycho-educational approach benefits the most when it focuses both on behavioral and attitudinal change. This has been highlighted by one of the effective strategies called the 'health literacy'. Health literacy refers to the individual's capability to acquire, process, and understand health information and services in order to make health decisions (Rawson et al., 2009). Low level of health literacy is associated with poor health status, increased hospitalization, low adherence to treatment regime and low self-management (DeWalt et al., 2004). Health literacy includes: recognition of the illness, knowledge and beliefs about the causes, self-help and professional help regarding the illness, how to seek information about the illness. These factors provide insight about the illness and ways to manage it. Psycho-education to the patients can be provided through individual patient counseling given by health care providers, lectures, demonstrations or written instructions. However, psycho-educational strategies alone have less impact as compared to strategies combined with behavioral interventions.

# **Behavioral Interventions**

One of the important strategies of behavioral interventions is problem-solving technique which is proven to be useful for treatment and prevention of various medical problems (Falloon et al., 2007). Problem solving techniques aim to change the individual's 'problem orientation' which refers to the way individuals perceive their everyday problems and how confident they feel at using problem solving strategies. Problem solving techniques help individuals in recognizing the problems (motivation), the normalization of the personal experience of the problem in their life, and development of skills in identifying the causes of problems accurately (Chang, Downey, & Salata, 2004). This technique helps individuals to view the problem as a challenge to overcome and a disaster to avoid, and improve their self-efficacy.

Another behavioral strategy for improving adherence is to initiate prompts or cues to remind patients to engage in health –enhancing behaviors such as taking medication, consulting the clinician at regular or timed intervals. Electronic technology is also used to remind patients by sending e-mails or text messages (Cutting Edge Information, 2004).

Tailoring or customizing the treatment regimen to suit the patient is also another method. This involves simplifying the medication schedule, pill organizers and accommodating the treatment regime into the daily habits and routine of the patient. Graduated regimen implementation is a technique which reinforces successive progression to the desired behavior. These kind of shaping techniques are suitable for exercise, and diet. Another technique named contingency contract or behavioral contract is an agreement mostly in a written form between the patient and clinician that promises some reward to the patient depending on their adherence. These should be negotiated and agreed for at the beginning of the treatment procedure (Gans & McPhilips, 2003).

### Cognitive-behavioral Interventions

Many aspects of the cognitive behavior therapies (CBT) have been used to develop adherence interventions. The aim of the cognitive behavioral technique is to make patients involved in their treatment and seek to identify the factors that hinder adherence (Gray et al., 2004). Motivational interviewing (MI) (Miller & Rollnick, 2002) is a CBT- based technique, which aims to alter the patients' motivation and prepares them to execute the positive changes in their behavior. This technique involves the clinician who discusses with the patient to understand their reasons for or against behavior change with empathy, clarifies his/her goals and compares them to the current harmful health practices and motivates the patient in planning ways to modify the behavior of match the goals. This is a patient-centered technique, as the focus is to understand the patient's perspective, instead of the clinician. The patient's inclination for change is thought to emerge from two factors: the significance of change from patient's perspective, and the patient's self-belief to engage in the change process. Confidence to change relates directly to the self-efficacy of the patient, which is a good predictor of treatment outcome (Burke et al., 2003). This technique was also found to be effective with adolescent diabetics to improve their adherence (Channon, Huws-Thomas, Gregory, & Rollnick, 2005).

The ultimate goal of all these approaches is to increase self-regulation. To reach this goal, patients do need help and support from family members, friends, clinicians initially till they gain mastery over their own health. However, in giving prime importance to adhering to all aspects of the treatment regimen, patients, clinicians and health professionals focus more on achieving optimal blood glucose control and to reduce the risk of long-term complications. While it is of paramount importance to address the medical outcomes and parameters, it is of greater importance to view health in a holistic and global manner and consider the overall wellbeing of the patient. This has become all the more crucial because with increased life expectancy, there has also been an increase in the number of years spent suffering from chronic and non-life threatening illnesses. This has led to improved standard of living shifting the actual health concern to the quality of life of the patients from just focusing on the absence of disease (Antonovsky, 1979; Dahlgren, & Whitehead, 2007). Medical parameters can be measured objectively (blood glucose levels, reduced symptoms), but to measure patient's quality of life requires their subjective perception of how their illness and treatment have affected the overall psychosocial functioning and the psychological distress that they experience. Patients suffering from chronic illness such as diabetes are likely to suffer from depression, anxiety, distress and low quality of life (Mittermaier et al., 2004), which in turn increases the risk for disease-related complications and vice-versa (Fal et al., 2011). Hence, there is an increasing recognition of the fact that patient's quality of life or wellbeing is an equally important outcome as the more traditional biomedical measures are. Issues related to the individual's quality of life are important as it predicts their capacity to manage the health condition, maintain their long-term health and well-being (Singh & Bradley, 2006).

# **Quality of Life**

The WHO (1995) defines QOL as "an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." The concept of quality of life (QOL) is multidimensional encompassing an individual's subjective perception of the "goodness" of different aspects of their life. These aspects involve one's physical functioning, psychological status, emotional responses to life events, disposition, social functioning, also includes cognitive component (sense of satisfaction and fulfillment), and emotional component (happiness with work and personal relationships) (Diener, Suh, Lucas, & Smith, 1999; Kahn & Juster, 2002).

The terms 'quality of life' and 'well-being' are often used together as an alliterative phrase. Similar to QOL, well-being refers to physical, psychological, and social states that are distinctively positive. According to Seligman (2002) well-being includes feelings of engagement interest, pleasure, meaning and purpose, and is a subjective perception of vitality (energy) and feeling well. The concept of well-being consists of two components: *subjective well-being* or hedonic perspective of well-being which focuses on happiness, positive affect and pleasure and secondly *psychological well-being* or eudemonic perspective of well-being, which focuses on fulfillment of human potential and realizing purpose in life (Ryan &Deci, 2001; Keyes, Shmotkin, & Ryff, 2002; Ryff, Singer, & Love, 2004; Waterman, Schwartz, & Conti, 2008). These two aspects of well-being are related yet distinct.

Subjective well-being (SWB) is defined as 'a person's cognitive and affective evaluations of his or her life' (Diener, Oshi, & Lucas, 2002). It can be understood as a

state of happiness, sense of satisfaction with overall and specific areas of one's life such as health, relationships, and work. It also has an emotional aspect (positive and negative affect), and a cognitive aspect (of judgments about one's life satisfaction). The affective aspect refers to management of positive and negative emotions and avoiding the negative affect completely rather than continually being in a positive emotional state. In other words, it implies as maximizing pleasure and avoiding or minimizing pain (hedonistic perspective). The cognitive aspect refers to the individual's perspective of their own life satisfaction in general terms (life as a whole) as well as in terms of specific dimensions of life (such as work, relationships, etc.).

Psychological Well-being (PWB) is based on the idea of universal human needs, effective functioning and realizing individual human potential (Ryan & Deci, (2001). It is a state characterized by acceptance, contribution, coherence, integration with others, and actualization (Keyes, Shmotkin, & Ryff, 2002). While subjective well-being refers to avoiding negative affect and being in a positive affect, psychological well-being refers to affective functioning. Psychological well-being involves perception and engagement with existential life challenges (Keyes, Shmotkin, & Ryff, 2002). Ryff (1989) proposed six dimensions of psychological well-being namely; autonomy, personal growth, self-acceptance, life purpose, environmental mastery, and positive relatedness. Ryff and Singer (1996) showed that the indicators for these six dimensions positively influenced mental and physical health, which subjective well-being did not necessarily contribute to.

Based on these two concepts of subjective well-being and psychological wellbeing, it can be said that QOL implies satisfaction with life (relationships, work, etc), effective management of emotions (both positive and negative), effective functioning and realizing one's full potential. Therefore the global QOL can be understood as an individual's appraisal of overall life experience at a certain point of time.

# **Factors Affecting QOL**

There are many factors that affect one's quality of life such physical, emotional, intellectual and social.

Physical factors that affect QOL include factors such as physical health, provision of balanced diet, comfort, physical safety, hygiene and exercise. Being in good health is an essential factor that contributes to one's quality of life. Apart from the basic factors such as health, safety and comfort, exercise also plays a vital role that enhances the sense of well-being in the individual and has long-term benefits.

Emotional factors such as happiness, satisfaction in life, autonomy, psychological security, privacy, dignity and approval from others play a role improving one's QOL. Every individual seeks a certain degree of privacy, to have a personal space and autonomy to decide, pursue, and accomplish their goals both personal and professional. Factors such as dignity, respect, receiving affection and praise for an accomplishment boosts one's self-esteem and subjective well-being. Individuals also seek to have psychological security and not to be worried and anxious about any aspect in their life. Constant worry or anxiety do tends to affect one's QOL negatively.

Having an active intellectual life also influences one's QOL. An intellectually stimulating environment helps individuals to stay intellectually active and alert. This helps individuals in staying engaging, motivated and challenged, making their lives interesting and warding off depression, thereby contributing to their QOL. Apart from engaging intellectually, learn a new skill, participating in voluntary work, taking up a hobby provides a sense of well-being. These activities also promote social interaction and physical fitness.

A healthy social life is a significant contributor to one's QOL. Having a close personal relationship with significant others, family and friends provides individuals with the needed support and emotional security to face problems and deal with difficult situations. Possessing psychological support of family and friends and their physical presence in times of need goes a long way in influencing one's QOL.

Factors such as these influence overall QOL. However, in order to understand QOL in the context of health and disease, one needs to look at 'health-related QOL' (HRQOL). The concept of QOL among patient groups needs to be understood in slightly different manner as Johnston and Pollard (2001), have pointed out that the relationship between impairment, disability and handicap is not to be anticipated but the relationship depended on psychological and social factors. Therefore an understanding of both the psychological and social factors that influence a person with disease is vital in order to arrest the disabling consequences of the disease.

### **Health-related Quality of Life**

HRQOL is associated specifically with health aspects including the global QOL components. HRQOL is a multidimensional concept which refers to evaluation of an individual's life experience and how they are impacted by the disease, its symptoms, treatments and accidents. HRQOL is related to an individual's optimal level of physical (energy, pain, discomfort, fatigue), psychological and emotional (thinking, concentration, positive/negative thinking), social functioning (personal relationships, social support, sexual functioning, home environment, leisure participation) including their role (parent,

spouse, career), relationships, life satisfaction and well-being (Bowling, 1995; Ferrans, 2005; WHOQOL, 1998). Bowling (1995), emphasizes the measurement of the patient's perception of health, fitness, level of independence (daily activities, mobility, work capacity) and health status, their satisfaction of the treatment (medication and treatment dependence), outcome and future prospects in order to understand one's HRQOL. The World Health Organization Quality of Life working group (WHOQOL) (1998) has added the components of personal, religious and spiritual beliefs to the already existing definition of QOL. Therefore assessing QOL among patient population is to determine the impact of the disease on the individual's functioning, the symptom severity, physical functioning or disability and consider these factors to indicate one's HRQOL.

# **Diabetes Specific HRQOL**

Considering the different nature of every illness, and diabetes being the focus of the study, HRQOL can be studied specifically from the perspective of diabetes. Diabetes specific HRQOL is a multidimensional construct and each domain independently influences an individual's QOL. It is the individual's perspective of how diabetes affects their functioning in physical, psychological, and social aspects (Polonsky, 2000). For example, factors such as the anxiety or worry that patients face about the consequences of the disease, the level of satisfaction with their lives and progress of the treatment, difficulty or ease of adjustment with the changed diet pattern, their coping style and diabetes specific self-efficacy, effect one's diabetes specific QOL (Polonsky, 2000).

# **Factors Affecting Diabetes Specific HRQOL**

Type II diabetes influences an individual's QOL in many ways. Various factors such as the illness factors, treatment factors, psychosocial factors and patient factors influence QOL.

# **Illness factors**

Illness factors such as appraisal of the illness, and the eventual coping with the situation also impacts one's QOL. In addition, poor metabolic control leads to diabetes related complications and early development of secondary diseases (National Health Priority Action Council, 2006). Complication such as impaired vision, kidney damage, sexual dysfunction neuropathic problems which may lead to difficulty in walking, loss of bladder control, may lead to reduced QOL. Cognitive dysfunction such as attention deficits or memory impairment affects both physical and psychosocial functioning of the patient (Murrell, 2001). The short term complications such as chronically high glycemic level can lead to frequent infections, fatigue, and sleep problems. These complications often impair daily functioning of the patient and may limit their work productivity and leisure activities. Drastic changes in lifestyle to manage their condition and the apparent side effects of the medication interferes their daily life and level of independence, thereby affecting their QOL.

### Treatment factors

Treatment factors also play a role in patient's QOL. Intensive treatment regimens aimed at lowering the glycemic levels involve highly demanding self-care regimes, which tend to lower the QOL (Rubin, 2000). During the course of treatment, effective interaction with the clinician and other health professionals lead to active coping style among the patients and enhances their QOL (Rose et al., 2002). Factors such as the choice of clinician, nature of communication, quality of health care amenities, continuity, accessibility and confidentiality, dignity, genuine attention and autonomy shown towards the patient, and prevention and early detection of complications influence QOL (Tabrizi, O'Rourke, Wilson, & Coyne, 2008). Providing the necessary knowledge about the condition and skills to manage the treatment process and learn new self-care behaviors improves patient's satisfaction with the treatment and their QOL (Deakin, Cade, Williams, & Greenwood, 2003).

# **Psychological factors**

Psychological factors are affected due to the demanding nature of diabetes selfcare. Predominantly, diabetes has a large impact on an individual's mood and affect (Mendlowicz, & Stein, 2001). Patients may become discouraged, frustrated, and feel hopeless as the condition may not respond to them despite their best efforts. They face emotional struggle to cope with the possibility of developing complications and mortality. Both chronically elevated blood glucose levels and frequent hypoglycemia can be alarming and lead to fatigue, exhaustion which can aggravate depressed mood and anxiety (Skarstein et al., 2000). Due to the complex nature of the disease which requires continuous monitoring of physiological changes, patients may feel an overwhelming sense of helplessness. Such emotional distress brings down the level of QOL to a great extent. According to self-regulation theory, hindrance caused due to a chronic illness in the attainment of personal goals, influences an individual's QOL (Scheier & Carver, 1992; Echteld et al., 2001). Appraisal of the event, and disturbance of goal attainment, appraisal of available resources and coping mechanisms together influence one's QOL. Hindrance in performing 'higher order' goals such as having fun, engaging in leisure activities and taking care of others was related to depression, anxiety and lower QOL (Boersma et al., 2005). Hindrance in reaching goals (day-to-day and higher-order goals) influences QOL and changes the 'meaning' an individual attaches to the illness (Taylor, 1983). The 'meaning' of illness can be understood as the individual's perception of the outcomes that the illness has on self, relationship with others, life's priorities, and future goals influence the QOL. Therefore psychological well-being of the individuals is compromised when their personal goals are hindered due to the presence of illness (Walker et al., 2004).

# Social factors

Social support plays a crucial role in the well-being of the individual and is related to coping and adjustment to any chronic disease (Suurmeijer et al., 2001). Perceived emotional and informational support influences QOL and mental functioning specifically in the first two years of diagnosis (Burgoyne & Renwick, 2004). For example, to manage diabetes following a strict diet regime is mandatory, however if the patient does not receive support and are discouraged by significant others, it may sabotage all their self-care efforts. On the other hand, if family members and friends compel the individual to make lifestyle changes, when they are unwilling to do so, may lead to interpersonal conflict and tension. Factors such as these, affect the individual's QOL, as diabetes becomes a part and parcel of their lives and affects every aspect.

# **Demographic factors**

The demographic factor of chronological age of a person may have lesser influence on their quality of life than the 'life stage' they are at. That is, the impact of illness on one's QOL depends on the time of occurrence during one's life, and whether or not a person is still reproductively and professionally active. For example, a young person who suffered a stroke and is unable to return to work would suffer greater loss of life satisfaction and well-being than a person who has had stroke in the post-retirement age (Vestling, Tfvesson, & Iwarsson, 2003). Likewise, those patients who are older (above 80 years) face a threat to their QOL if they are disabled and their independence challenged (Woods, 2008).

Culture of the individual also plays a role in one's judgment of their QOL. Factors such as attitude and beliefs towards traditional and western treatment methods, response to pain, understanding about dependency (in case of disability), and the dynamics of communication specific to each culture play a role in the way patient respond to illness, treatment and its management in liaison with health professionals and their significant others (Yan & Sellick, 2004).

The personality of the individual has also found to be a strong and significant predictor of well-being and life satisfaction (Diener, Suh, Lucas, & Smith, 1999). The coping style of the individual determines whether or not one can adapt and accustom to new situations and alter their goals likewise, which in turn will increase their QOL.

# **Benefits of Improved Quality of Life**

Diabetes education is considered to be an important tool to empower patients to take responsibility for their life and health condition and by teaching and developing skills to manage their condition effectively (Funnell, & Anderson, 2004). Similarly, selfempowerment leads to greater perceived quality of life (Delamater et al., 2001). Individuals with improved quality of life have better sense of self-efficacy, show greater adherence to treatment, attained therapeutic goals and better prognosis (Vinik & Zhang, 2007). Patients with better QOL reported to have experienced lesser frequency of hyperglycemic symptoms (Tabaei et al., 2004). Though QOL has a weak association with glycemic levels, improved glycemic levels reduced the occurrence of long-term complications (Nathan et al., 2007). Therefore, improved QOL not only improves over all well-being and productivity of the individual but also improves self-management of the disease and better regulation of the physiological parameters and delays the short and long term complications.

### Chapter II

# **Review of Literature**

Extensive research has been conducted on psychological variables related to diabetes management. This chapter focuses on the review of the literature available pertaining to the variables under study. Firstly, existing literature about the impact of diabetes on various aspects of a person's life has been reviewed in detailed. This gives an insight into far reaching effect diabetes has and to pinpoint the areas that can be improved in order to make the patients' lives more comfortable. Secondly, literature related to each variable under study will be reviewed in a systematic manner.

# **Diabetes and its impact**

Diabetes is not just a public health burden but it represents a personal challenge for those living with the condition. And with no cure available the challenge to manage the condition is a never ending one for both the patient and their families (Barnard & Lloyd, 2012). Living with diabetes can be understood as complex and demanding often accompanied with contradictory self-care directives leaving the patients angry, frustrated, discouraged and overwhelmed. It is not just demanding on the personal level, but interpersonal relationships may become strained and interactions with health professionals may become challenging which adds to the distress related to diabetes (Polonsky et al., 2005).

# **Impact of diagnosis**

Receiving the news of being diagnosed with diabetes is often accompanied by the response of shock which can sometimes be followed by the response of anger, denial

before finally accepting and coming to terms with the reality (Bowes, Lowes, Warner, & Gregory, 2009). Patients often blame themselves for being diagnosed with the condition, and refuse to share their diagnosis with their friends and extended family members. Being labeled as a "diabetic" has the potential to set aside the individual from what the society calls or labels as "normal" or "healthy" (Barnard & Lloyd, 2012). These societal norms come along with prejudices and unwritten rules about how a diabetic has to behave. People with diabetes report very often of the stigma attached with the condition, which not only affects their health but also social functioning (Barnard & Lloyd, 2011). The social stigma surrounding diabetes, though under-researched is a potentially significant aspect that influences the acceptance of the condition. Even though persons without diabetes assume that there is no stigma attached to the condition, those who suffer from diabetes report that the issue of stigma is of significant concern to them. The stigma is experienced across the domains of life such as at workplaces, and in relationships which impacts the psychological well-being and self-care of the patients (Schabert, Browne, Mosely, & Speight, 2013). From her personal experience, Amy Stockwell Mercer, a patient suffering from Type 1 diabetes, reports that for years she avoided taking insulin shots, testing her glucose levels when in public, and though it has been 27 years since being diagnosed, she is not comfortable sharing that she suffers from the condition due to the stigma attached to it (Mercer, 2013). The stigma attached to diabetes also tends to influence patients to compromise on their self-management decisions. In a study conducted by Wellard, Rennie, and King (2008), patients reported that they faced social stigma due to their food choices which also affected their family relationships.

# **Coping process**

The process of accepting that one has diabetes, has been found to be similar to the grieving process. Coping at each stage of this process impacts how well the individual accepts his/her condition and their ability to adapt and perform the necessary selfmanagement behaviors in order to manage the condition (Bowes, Lowes, Warner, & Gregory, 2009). It is important to identify and support patients whose ability to adjust and cope can be affected by their psychosocial situations and reaction to their diagnosis (Rane, Wajngot, Wandell, & Gafvels, 2011). Rane and colleagues (2011), conducted a study on 106 newly diagnosed diabetes patients, upon interviewing 41.5% of the patients were found to be experiencing psychosocial problems. More than half of them reported to be having problems in their relationships and one-third of them attributed it to workrelated problems. Compared to other participants in the study, those who had psychosocial problems lived in socially strained situations especially in personal finances and social support. These patients were found to be more anxious, depressed and used negative coping strategies more often which would have a negative impact on their condition in the future. The concept of diabetes fatalism, a term which is used to describe the complex psychological cycle marked by perceptions of despair due to emotional distress, perception of low self-efficacy leading to powerlessness, and hopelessness, is often found in diabetes patients across various durations of disease and more so among newly diagnosed patients (Egede & Ellis, 2010). Studies have shown that diabetes fatalism is associated with poor glycemic control among diabetics. Fatalistic beliefs act as a barrier to effective diabetes self-management, quality of life and optimal glycemic control (Egede & Banadonna, 2003). In a study conducted by Osborne and Egede (2010),

diabetes fatalism was indirectly associated with glycemic control through self-care measures such as overall diet, specific diet, blood glucose testing and foot care. In a study conducted by Walker and colleagues (2012), diabetes fatalism has been found to be significantly associated with poor medication adherence and poor self-care behaviors in terms of diet, exercise and blood glucose testing.

### Support of health-care providers and patient interaction

It is during the time of diagnosis that the role of social relationships becomes crucial to help cope with the changed status of being "healthy" to being diagnosed with a chronic illness. More importantly the relationship between the patient and the health care team is a fundamental one as the patient faces the daunting task of not only coming to terms with the diagnosis but also to understand the nature of the illness (Barnard & Lloyd, 2012). Of the many diverse needs, the most important need of the patient is to receive and assimilate new information regarding the illness, fears about their health need to discuss and patients also seek to learn new tasks in order to manage diabetes. These new tasks include acceptance and readiness to bring about lifestyle change, and adjusting to the new treatment regimen (Barnard, Lloyd, & Holt, 2012).

Providing support to the patients to helps them to deal with the daily burden of diabetes, the emotional and psychological impact and complements their self-management. For providing this support health professionals need to have empathy for the patient and an understanding of the psychosocial needs of the patients in addition to the biomedical needs (Schoenthaler, Schwartz, Wood, & Stewart, 2012). The relationship between the patient and the health-care provider is built on good communication and effective use of language (Dagogo-Jack, Funnell, & Davidson, 2006).

In an extensive review done by Puder and Keller (2003) ascertains that the healthcare provider's beliefs, attitudes and knowledge about diabetes influences the patient's self-care behavior and adherence to treatment regimen. The clinician attitude affects the patient not just during the treatment but right from the time of diagnosis.

According to a study conducted by Dietrich (1996) clinician's attitude at the time of diagnosis was crucial in formation of patient's attitudes about the seriousness of the condition and the self-management behavior that would follow. Good and empathetic communication predicts good diabetes self-care and diabetes outcomes (Schillinger et al., 2003).

In a study conducted on 367 patients suffering from Type 1 and Type II diabetes found that the poor quality of patient-provider communication was associated with poor adherence to treatment (Ciechanowski, Katon, Russo, & Walker, 2001; Rodriguez, 2013). This highlights the importance and the need for effective, empathetic communication between the clinician and the patients, supporting them by providing the necessary information related to the condition (Delamater, 2006).

Receiving such support from the health professionals is crucial for adjusting with diabetes as it puts the disease into context along with other life priorities. This kind of an understanding is necessary to avoid being overwhelmed and controlled by the disease. Studies show that flexibility in treatment and greater access to health education enable individuals to accommodate diabetes into their lives rather than the contrary where one's life revolves around diabetes (Barnard, Lloyd, & Holt, 2012). This helps in maintaining a

balance between the severity of the condition while enjoying the autonomy and good quality of life, minimizing the impact of any limitations caused by diabetes.

### Impact of treatment and management

# Impact of medication and lifestyle modifications

Persons with diabetes are not only affected by the condition but also due to the treatment required to manage it which involves a number of aspects such as medical treatment, lifestyle changes and self-management tasks (Rubin, 2000). Persons with Type II diabetes need to adapt to oral medications or insulin injections and lifestyle modifications to maintain optimal health and reduce risk of complications. Daily management of diabetes is particularly stressful for the patients as it includes dietary modifications, adequate physical activity, weight regulations, and daily or weekly glucose monitoring and regular check-ups. In addition to these modifications, the interaction of short-term and long-term emotional distress along with coping with social situations adds to the burden of diabetes management (Peyrot et al., 2005). Many patients find the lifestyle management and treatment regimen to be constraining as it hinders their flexibility with the schedules. Even those patients with optimal glycemic control report low quality of life due to the difficulty in executing these lifestyle changes (Stanetic, Savic, & Racic, 2012).

Patients find it difficult to adapt to necessary treatment required to control the glycemic level. For example, clinicians are reluctant to start insulin therapy due to reasons such as patient's attitude and beliefs pertaining to diabetes and its treatment (Davis & Renda, 2006). It has been reported that patients perceive insulin therapy as an outcome of personal failure and a sort of punishment for failing to manage their condition

well. Resistance to insulin use is influenced by factors such as negative self-perceptions, fear of side effects and complications, attitudinal barriers, restrictions that are mandatory during insulin use, and most importantly social stigma (Brod, Kongso, Lessard, & Christensen, 2009).

Patients fear the embarrassment, social stigma, fear of weight gain, increased risk of hypoglycemia, fear of self-injecting, disliking daily injections and experience general anxiety, which hampers effective treatment of the condition (Reid, 2007). However, studies show that insulin therapy can affect quality of life positively by controlling the high blood glucose levels (Gerstein et al., 2011) and clinicians can alleviate fear of the patients regarding insulin use by actively listening to them and providing them required information about the rationale of using it (Sorli & Heile, 2014). In addition to the distress related to diabetes management and treatment, the knowledge of the fact that poor self-management or poor diabetes control can lead to increased risk of diabetesrelated complications can be an additional stressor to the person (Singh & Bradley, 2006).

#### Psychological impact of the treatment and management

Diabetes management has a significant psychological impact. Persons suffering from diabetes are more likely to suffer from depression than the general population (Lloyd et al., 2010; Pouwer, 2010). One-third of those suffering from diabetes have a lifelong risk of developing clinically relevant depressive disorders (Anderson, Freedland, Klaus, & Lustman, 2001; Barnard, Skinner, & Peveler, 2006; Gendelman et al., 2009). According to research the relationship between diabetes and depression appears to be bidirectional with the presence of depression increasing the risk for diabetes (Nouwen, 2010).

A study conducted in the UK found a four-fold increase in the risk of diabetes in depressed men and one-and-a-half time higher risk in women (Holt et al., 2009). Furthermore, the study showed that depression was associated with both diagnosed and undiagnosed diabetes suggesting that psychological distress experienced due to disease diagnosis is not the only reason. There may be other reasons such as poor social support; constant practical and emotional burdens that accompany diabetes self-management may also play a vital role in the increased risk for depression (Pouwer, 2003). The counter argument could be that depression among diabetes patients may lead to poor selfmanagement which directly impacts their blood-glucose and increases the risk of developing diabetes related complications (Katon et al., 2005; Kovacs & Obrosky, 1997; Lustman et al., 2000) and lowers their quality of life (Schram, Baan, & Pouwer, 2009). In addition, an estimated range of 31% to 45% of diabetes patients suffers from subclinical depression who often do not receive treatment and are left to cope alone. While the presence of symptoms related to depression in diabetes patients is a known fact, research still needs to differentiate between diabetes related distress, diabetes burnout, and depression to administer proper care and treatment (Holt et al., 2009; Lloyd et al., 2010; Nouwen et al., 2010; Pouwer et al., 2003; Pouwer et al., 2010).

Apart from those who suffer from depression, substantial number of persons suffers from diabetes-related distress or experience diabetes burn-out which can be defined as "overwhelmed by diabetes and by the frustrating burden of diabetes self-care" (Polonsky et al., 1995). Though diabetes burn-out is different from depression, it can still have destructive and serious implications for diabetes care. Persons suffering from diabetes burn-out feel defeated and controlled by diabetes, are overwhelmed and frustrated by the self-care regimen, feel alone and isolated due to the condition. Thus, while diabetes burn-out involves negative feelings about diabetes, depression as a comorbid condition along with diabetes, is a physical and psychological disorder. Research needs to be carried out to address the burden of balancing diabetes with other demands such as people's time, energy, stress, and workload.

#### Impact of diabetes treatment and management on family members

Persons with illnesses, do not suffer from the condition in a vacuum, but their illness exists within a given personal context, social network and culture. The impact of diabetes and its management is not just felt by the person suffering from it, but also by others like family members and friends. Along with the patient, the family needs to adapt to the changes that the illness brings. Right from the diagnosis, tests and treatment can have an impact on the coping of the family, the uncertainty about the future and their life goals (Sherman, & Simonton, 2001). The process of adapting to the illness can disrupt the family system. It can impact the daily functioning, work, family relationships and social life. The quality of life of the family is compromised along with that of the patient. Studies have shown that the family members face limitations and anxiety associated with living with the person suffering from diabetes (Barnard, Speight, & Skinner, 2008). For instance, increased physical health issues are noticed among family members of diabetes patients who also suffer from depression. In case of families where there is child suffering from Type 1 diabetes, the quality of life of the family members is adversely affected by the child's diabetes and treatment regimen. Especially when the child

approaches adolescence and young adulthood parents tend to be concerned of the child's ability to cope with the new responsibilities as they move away from the parents to university or to start a new job or to establish a new long-term relationship (Barnard, Speight, & Skinner, 2008).

#### Impact of the interaction between the patient and health-care system

Difficulty in adapting with the condition may not just arise due to coping issues of the patients but also can be due to the gap in communication between the patient and the health-care provider. There can, sometimes, be a mismatch between the self-management goals of the doctors and the patient. While the health care professionals may focus on medical outcomes and to minimize the risk of complications, the patient may be concerned about managing their daily life and diabetes simultaneously. Challenges such as managing food intake in accordance to the energy levels, altering daily routine to accommodate regular physical activity, scheduling doctor's appointment into an already busy schedule can become important concerns (Barnard, Lloyd, & Holt, 2012). Health care professionals need to be aware of such concerns and work with the people to resolve such issues by helping them develop realistic attitude and expectations about treatment goals and self-management. The concept of shared decision-making (SDM), advocated by the health care and clinical policies is yet to be implemented in diabetes care (Tamhane, Rodriguez-Gutierrez, Hargraves, & Montori, 2015). The process of shared decision-making (SDM) is a two-way dialogue between the patient and the clinician to identify suitable disease management options that addresses the unique situation of the patient. The SDM implements the principle of evidence-based medicine, in which a clinical decision is made not just based on evidence and different treatment options but

only after considering the context and preferences of the patient. SDM is appropriate to diabetes care as a decision is made after collaboration between the clinician and the patient involving the process of considering different management options that vary from patient to patient and choosing the best option. Customizing the treatment and management regimen to the needs and preferences of the patients is necessary as the management pattern places a considerable demand and strain on the patient's daily life.

#### Financial impact of diabetes treatment and management

Lastly, the impact of diabetes is not just on the physical, psychological and social aspects but also on the financial aspect. Since it is a chronic condition mostly associated with complications and co-morbidities, it does have a significant impact on the cost of daily and long-term care (Esteghmati et al., 2009). The estimated annual cost for India in the year 2011 due to diabetes was about \$38 billion (Tharkar, Devarajan, Kumpatla, & Viswanathan, 2010). The cost of treatment of the disease is increasing by 20-30% every year. The annual expenditure in the year 2016 is estimated at 1.5 lakh crore rupees, which is 4.7 times more than the budget allocated for health (Times of India, 2016). An extensive study was conducted by Tharkar, Devarajan, Kumptla and Viswanathan (2010) in which 1050 diabetes patients were surveyed and interviewed to estimate the socioeconomics of diabetes in India. The surveyed sample consisted on both male and female patients, who received treatment through different types of health care centers such as private clinics (38%), government hospitals (18%), and super-specialty clinics (44%). The sample also consisted of patients belonging to different income groups and there was an equal distribution of severity and chronicity of the illness with 68% of then suffering from at least one condition. The study attempted to estimate the financial

burden faced by both the person and the country on the whole. It was found that the direct cost per year incurred by a person due to the illness was estimated to be 25,391INR, of which 12,992 INR was incurred during the hospital admission, 8595 INR was spent on drugs and monitoring costs and 2932 INR for two out-patient visits per year.

Studies show that greater financial burden is experienced by those who have an associated co-morbid condition along with diabetes than those who suffer from diabetes alone Tharkar, Devarajan, Kumptla and Viswanathan (2010). Similar results were found by Tharkar and colleagues (2010), the direct cost of treatment incurred by the patients who do not have any complications was found to be 6520 INR per annum while those patients who had three or more complications spent about 32,500 INR per annum on their diabetes care.

In India, people lack access to health care services, and there is a dearth of national welfare schemes and health insurance coverage for diabetes treatment (Narayan et al., 2006). This puts a strain on family's income thereby affecting the opportunities, facilities and quality of life on the whole. For instance, when an adult from low-income family suffers from diabetes, approximately 25% of the family's income is devoted to the diabetes care of the person (WHO, 2013).

According to the study conducted by Tharkar and colleagues (2010), 60 % of diabetes patients belonging to the higher income group in India met the expenditure incurred due to diabetes treatment and management mostly from personal savings. Whereas 40% of the patients from the lower income group met the expenditure through selling or mortgaging properties such as land, house, etc or through borrowing loans at higher interest rates. The study showed that though diabetes is highly prevalent in higher socioeconomic group, complications are higher among low income group, thus putting more financial burden on those from lower income group. There is little help received from insurance coverage, as insurance companies in India do not provide total coverage for diabetes. Only 2% of patients belonging to higher income group depended on insurance while those from lower income group did not have health insurance.

On the whole it can be understood that there are few issues which are found to be particularly stressful by diabetes patients in the management of diabetes. They include management of daily tasks related to diabetes care (e.g., adherence to medication, physical activity, dietary pattern, etc), the interaction between acute and chronic emotional distress associated with glycemic control and coping with interpersonal conflicts and social situations (Peyrot et al., 2005). Therefore the nature of diabetes is such that, the biological aspect, the psychological aspect and the social aspect, all three aspects of a human being get affected.

While the biological aspect is treated with medication, very often the psychological and social aspects of the patient are neglected. Some of the psychosocial barriers related to diabetes-distress and poor self-management include negative beliefs and attitudes, financial resources (Burge, Lucero, Rassam, & Shade, 2000), low self-efficacy (King et al., 2010), external locus of control, low level of knowledge related to diabetes, low social support (Sarkar, Fisher, & Schillinger, 2006), low adherence (Rodriguez, 2013), and poor quality of life (Steed, Cooke, & Newman, 2003). Therefore in order to cope with the illness, a person would help and support in these three areas. The specific interest of this study, therefore, has been on few of the above variables. It has been endeavored to understand the impact of diabetes knowledge, social support, and

self-efficacy on adherence and quality of life diabetes patients. In rest of this chapter, existing literature has been reviewed related to the variables of interest.

## **Knowledge of Diabetes**

One of the barriers to achieve optimal control of diabetes is the lack of the required knowledge concerning various aspects of the disease. As mentioned earlier, knowledge of an illness comprises of broad range of information and understanding regarding its symptoms, causes, complications and management strategies. Knowledge of these aspects of any illness has been shown to be instrumental in coping with the illness. Several studies have been conducted to demonstrate this. Especially among patients suffering from chronic illnesses such as hypertension and diabetes patient education plays an important role in achieving adequate control and in preventing adverse health complications.

Patient education plays a facilitating role in helping diabetes patients to accept their condition and diagnosis and in understanding lifestyle changes such as following diabetic diet, insulin regimen, and blood glucose monitoring (ADA, 1996; Williams, Baker, Parker, & Nurss, 1998). Studies have shown that educating patients with Type II diabetes was seen to have positive effect on metabolic control, preventing acute and chronic complications and in improving quality of life. This effect was mediated by the changes in knowledge, attitude and patient behavior (Falvo, 2004; Snoek, & Visser, 2003).

Research shows that patients who possess information about their illness and its treatment regimen tend to manage their illness in an efficient manner (Ellis et al, 2004). For instance, hypoglycemia, which is one of the most common difficulty any diabetes

patient faces, can be prevented by regular blood glucose monitoring (Banerji, 2007). Imparting knowledge and educating patients in such health care behaviors facilitates in bringing about significant changes in their lifestyle.

However, studies carried out in various communities with diverse socioeconomic and cultural backgrounds (Knight et al., 2005) show that knowledge about self-care activities is a crucial element in diabetes treatment, studies in India (Hawal, Kambar, Patil and Hiremath 2013), show that diabetes patients lack knowledge on various aspects of diabetes.

#### Knowledge of diabetes and social support

Research has found a relationship between social support, patient education and self-management of Type II diabetes patients. According to American Diabetes Association (2015), diabetes self-management education and support (DSME/S) programs need to be provided for all the diabetes patients. DSME/S helps to fill the gaps in patients' knowledge of the disease, physical limitations, emotional concerns in order to positively impact the patient's ability to rise up to meet the challenges of the disease. Diabetes self-management education (DSME) is the process of providing the required knowledge, ability and skill needed for diabetes self-care activities and diabetes self-management support (DSMS) indicates to the support that is essential for executing and sustaining the behaviors and coping skills consistently on a daily basis. DSME/S also helps patients in making diabetes treatment-specific decisions smoothly. Providing DSME/S was found to be beneficial in many ways such as reducing and regulating the blood glucose levels effectively (Steinsbekk et al., 2012), delayed the onset and reduced the progression of diabetes related complications (Stratton et al., 2000), enhanced QOL

(Cooke et al., 2013), engagement in lifestyle behaviors such as maintaining diet and increasing physical activity (Toobert et al., 2011), self-efficacy (Tang, Funnell, & Oh, 2012) and healthy coping (Thorpe et al., 2013).

A one-year patient advocacy intervention among rural Mexican farm workers showed significant improvement in their glycemic control (Ingram et al., 2007). Similar results were found after a 6-months intervention involving group and individual social support among Type II diabetes patients. There was significant increase in the participants' diabetes knowledge and their self-management behaviors among individuals who reported to have high social support (McEwen et al., 2007).

A study conducted by Tiv and colleagues (2012) to measure medication adherence among Type II diabetes patients in French population base found that variations in level of adherence to treatment. Among many reasons for poor adherence, reasons such as lack of social support from family and medical professionals, lack of knowledge and information about the treatment were also quoted. Others reasons included age, place of origin, difficulty in taking medication alone, having to decide all by oneself, and others. The study indicates the role played by support from family and medical professionals and also the importance of knowledge in adherence behavior.

Studies have shown that those individuals who have history of diabetes in the family have a higher level of knowledge of diabetes (Azinge, 2013; Al Shafaee et al., 2008), however among adolescents the level of knowledge about diabetes was not influenced by the history of diabetes in the family (Okoh & Jaja, 2014).

#### Knowledge of diabetes and self-efficacy

Many studies have been conducted to establish the relationship and impact of knowledge about an illness and the self-efficacy of the patients.

A study conducted on eighty Type II diabetes patients to evaluate the effect of patient education on their knowledge level, self-management and self-efficacy found a marked improvement in outcome measures after the intervention involving the education program. The researchers found a limited effect on patient's knowledge and their self-management behaviors however; there was a significant effect in their self-efficacy (Atak, Gurkan, & Kose, 2008). Among patients suffering from cardiovascular disease, a significant increase was found in every aspect of self-efficacy due to the effect of education (Baljani et al., 2012).

A study conducted on Type II diabetes patients by Bayat and colleagues (2013) to assess the effect of diabetes education intervention which was based on health-belief model showed that the interventional program had a significant and positive impact on constructs based on health belief model. There was a significant positive impact on perception of susceptibility, benefits, severity and overall impact on self-efficacy. The results also showed a decrease in the perception of barriers to self-management of the diabetes treatment regimen. In this extensive study, it was found that the level of selfefficacy showed consistent increase after the intervention and also after the 6 month follow-up period. This indicates that the patient's self-efficacy can be significantly improved by systematic patient education.

Similar results were found in a study which aimed at examining the effect of an intervention aimed at increasing physical activity among Type II diabetes patients found

that the participants' self-efficacy for engaging in physical activities improved markedly after the intervention (Heijden, Pouwer, Romeijnders, & Pop, 2012). A study conducted on cardiovascular patients by applying a education program also showed increase in every aspect of self-efficacy (Baljani et al., 2012).

#### Knowledge of diabetes and adherence

As mentioned in earlier studies, knowledge of a disease impacts adherence to the treatment regimen. A study conducted in southern India showed the low level of medication adherence in diabetic patients (Sankar et al., 2013). Research shows that possessing low levels of health literacy and specifically among diabetes patients it was seen to be associated with low level of adherence to treatment and poor self-management and health, and frequent hospitalization (DeWalt et al., 2004).

Further, research has shown that acquiring knowledge about diabetes influences individuals to make better health choices and improves their adherence to medical recommendations (Pongmesa et al., 2009). Possessing better knowledge about diabetes has been associated with increased inclination to perform self-care activities such as regular exercise, sticking to diabetes relevant diet (Persell et al., 2004); perception of fewer barriers to blood glucose monitoring (Murata et al., 2003); better adherence to medication (McPherson, Smith, Powers, & Zuckerman, 2008); and better glycemic control (Al-Qazaz et al., 2011).

A study conducted on 288 Type II diabetes patients to assess the adherence and related factors contributing towards anti-diabetic medication regimen found that the level of patients' education, duration of their disease, knowledge about diabetes mellitus and its medication had a significant positive impact in adhering to treatment (Abebaw, Messele, Hailu, & Zewdu, 2016).

However, patients require both intrinsic and extrinsic motivation in addition to knowledge about the disease and its management to ensure higher compliance to the treatment regimen (Shobhana, Begum, Snehalatha, Vijay, & Ramachandran, 1999).

#### **Knowledge of Diabetes and QOL**

Knowledge of various aspect of diabetes has been found to affect one's QOL. While few studies show a positive impact of knowledge on QOL, others have also found a negative impact of knowledge on QOL.

A study conducted by Kalda, Ratsep, and Lember (2008), found that QOL was significantly affected by one's age, body mass index and duration of their disease. The greater the patients' age, duration and BMI was, the lower their QOL. An interesting finding of the study was that the less aware the patients were about their condition, the greater was their QOL.

A cross-sectional study conducted by Kueh, Morris, Borkoles, & Shee (2015), to understand the relationship between diabetes knowledge, attitudes and QOL found a negative relationship between age, duration of disease and diabetes knowledge. The study found that knowledge about diabetes did not affect QOL directly. However, knowledge impacted QOL in an indirect manner by initially affecting attitudes and then by influencing self-management behaviors such as blood glucose monitoring. Therefore knowledge impact attitudes and self-care behaviors which then improves one's QOL.

Similar results were found in a study conducted by Zhang, Wee, Tan, Thumboo, & Li (2009), where it was found that diabetes knowledge had predicted diabetes specific

QOL and overall HRQOL, only when it was studied in relation with other variables such as age, gender, duration of disease and other medical complications.

#### Social support among diabetes patients and related variables

Social support plays an important role in sustaining, and protecting one's health and in nourishing one's well-being (Harrington, 2013). Studies have consistently shown that the quality of social relationships predicts subjective well-being (Diener & Seligman, 2002). An empirical study conducted by Pinquart and Sorensen (2000) found that selfesteem, life satisfaction, and happiness index showed a stronger relationship with quality of social contacts than with the quantity. Such kind of social relationships were found to have positive relationship and impact on enhanced health and greater longevity (Graham, Christian, & Kiecolt-Glaser, 2007; Uchino, 2006). For instance the result of a study showed that terminally ill patients lived 80 days longer than those who did not receive actual social support (Herbst-Damm, & Kulik, 2005).

Among those patients suffering from cardiovascular disease, it was found that those who received higher level of social support reported to have lower level of blood pressure readings, reduced occurrence of cardiovascular disease and slower progression of illness among those already suffering from cardiac problems (Uchino, 2006).

It has been indicated that social processes linked to social support provide and act as an encouragement to a person in maintaining healthier diet, increasing their physical activity and getting the required sleep. Following these health promoting behaviors act as protective factors against lifestyle related illnesses (Berkman et al., 2000; Steptoe et al., 2004). A substantial amount of work related to social support and its benefits found that those patients who have higher support from friends and family show better adherence to treatment regimens which helps in recovering from illness and in sustaining health behaviors (DiMatteo, 2004).

Research has shown the positive impact of social support on self-efficacy, and QOL. In a study conducted by Dur and colleagues (2004), the various health determinants namely social support, self-efficacy and job satisfaction were found to have a positive effect on well-being and overall health among patients suffering from Crohn's disease. These findings are further ascertained by a study conducted by Hale, Hannum, and Espelage (2005). They found that social support and the feeling of belongingness not only contributes to psychological well-being but also contributes to overall perception of good health. A recent study conducted on breast cancer patients found that women who had higher level of support from their spouses experienced more positive emotion and lesser negative emotions (Gremore et al., 2011); and those women who had unsupportive spouses reported higher distress (Manne, Ostroff, Winkel, Grana, & Fox, 2005).

Research has found that social support, namely emotional, tangible or appraisal support gives a person innate sense of meaning and purpose in life (Taylor, & Turner, 2001) which in turn was associated with health and well-being (Brown, Nesse, Vinokur, & Smith, 2003). Providing social support is not just beneficial for the receiver of support, but also for the provider (Harrington, 2013). It also has been found that those who have higher tendency of reaching out and providing support to others report lower levels of depression and higher well-being (Piferi & Lawler, 2006).

So far, the benefits of social support on mental health and QOL have been examined; however the specific effects on health outcomes have been mixed (Hogan, Linden & Najarian, 2002). There have been findings where psychotherapeutic interventions for cardiac patients showed no impact and peer support groups for cancer patients were noted to have negative impact on the patients (Helgeson et al., 2001). Receiving emotional or tangible support was found to be induce distress and was linked to lower well-being. In addition to this receiving support may evoke feelings of low self-worth for not being able to take care of oneself (Lepore, Glaser,& Roberts, 2008) and being indebted to the support provider (Marroquin, 2011).

Similar findings were reflected in a study conducted on Type II diabetes patients, where a culturally-tailored self-management and social support intervention was implemented for Mexican American adults. This intervention was aimed to impact behavioral and physiological outcomes. While there was a change in behavioral outcomes such as decrease in sedentary lifestyle, improvement in self-care activities, and increase in diabetes knowledge the physiological outcomes were not impacted to a significant level. However, there was significant impact on reducing distress levels related to managing the treatment regimen (McEwen, Pasvogel, Gallegos, & Barrera, 2010).

## Self-efficacy and adherence

The concept of self-efficacy helps in understanding the process by which individuals maintain and adhere to treatment consistently (Dimatteo, 2004). Possessing a high level of self-efficacy is often related to higher well-being through the lifespan (Maddux, 2009). Self-efficacy predicts the motivation level of engaging in health promoting behaviors, the apparent response to illness, and the implementation of the intended behaviors. It acts as mediating factor between non-adhering behavior and selfmonitoring of blood glucose levels (Ott, Greening, Palardy, Holderby, &DeBell, 2000). Individuals with high self-efficacy levels believe that they are in-charge of their health and possess ability to manage pain and show better adherence to improve their health condition (Brannon & Feist, 2000).

A study conducted by Mishali and colleagues (2010), to assess the influence of self-efficacy on adherence to diet, medication intake, engaging in physical activity showed that self-efficacy plays a crucial role in managing diabetes effectively. The study showed that low self-efficacy levels lead to low adherence to diet, exercise and intake of medication. Assessment of self-efficacy also helps health professionals to identify the areas in which patient is most likely to adhere and those in which they are less likely to adhere and intervene in those areas. Similar results were found when a study was conducted on adolescent girls suffering from Type 1 diabetes. The study revealed that low self-efficacy was one of the reasons for low adherence to medication (Griva, Myers, & Newman, 2000). A strong association was found between self-efficacy and self-management behaviors (Sarkar, Fisher, & Schillinger, 2006).

In a study conducted by Aljasem, Peyrot, Wissow, and Rubin (2001), found a relationship between perceived barriers, self-efficacy and self-care behaviors. Those individuals who were found to have high level of self-efficacy were reported to have lower levels of blood glucose, low frequency of binge eating, and followed a healthy diet. Sacco and colleagues (2005) found that high self-efficacy was associated with high adherence and decreased depression, while low-self-efficacy was associated with non-adherence to medication and depression.

#### Self-efficacy, adherence and QOL

Review of literature shows that self-efficacy is not only associated with better adherence but also enhanced well-being and quality of life. Studies show that a strong association exists between self-efficacy and adherence to self-care behaviors, which led to lower levels of blood glucose levels in Type 1 diabetes patients (Johnston-Brooks, Lewis, & Garg, 2002), improved quality of life and decrease in depressive symptoms (Grey et al., 1998).

Self-efficacy was found to have a mediating relationship between discrepancies in illness-related goals and quality of life of patients with chronic illnesses. This mediation acted as a catalyst in achieving the desired outcomes related to health. It also determined whether the individuals would initiate health enhancing behaviors and sustain their efforts in dealing with the obstacles in execute such behaviors (Kuijer, & De Ridder, 2003).

Rose and colleagues (2002) conducted a study to understand the physical and psychological factors that contribute in achieving primary treatment goals for managing diabetes and experiencing normal quality of life. The results of the study showed that in order to attain primary treatment goals, self-efficacy beliefs and active coping behavior had the greatest impact.

A study conducted among employed and unemployed married woman found a significant positive relationship between hardiness, self-efficacy, self-esteem, and quality of life. It was further found that those who had higher self-efficacy had better coping skills in order to handle any stressful situation, which in turn led to better physical and mental health (Azar, Vasudeva, & Abdollahi, 2006).

A study conducted among spinal cord injury patients found that perceived health, perceived social support, and self-efficacy were seen to influence the subjective wellbeing of these patients (Hampton, 2004). Among varied groups of cancer patients, selfefficacy was found to be associated with mood (Cunningham, Lockwood, & Cunningham, 1991), emotional well-being, cognitive functioning (Boehmer, Luszczynska, &Schwarzer, 2007), psychological adjustment (Hirai et al., 2002), and physical well-being (Hochhausen et al., 2007).

#### Adherence

Many factors influence whether a person adheres to the medical recommendations such as self-efficacy, individual differences, coping style, and personality factors among many others (Christensen, & Johnson, 2002). Patients whose health care providers insist and encourages adherence and provides the necessary information to the patients show higher rates of adherence behavior (Goldring, Taylor, Kemeny, & Anton, 2002). However, it may occur that individuals who are aware of the importance of adhering to treatment, and have a strong wish to adhere, may not be able to do so because of lack of self-efficacy or the confidence of carrying out those behaviors (Senecal, Nouwen, & White, 2000). The psychosocial factor of social support from immediate family members, friends lead to enhanced adherence and studies have shown that adherence is 1.74 times higher in those patients who have closely knit support network, cohesive families and adherence was found to be 1.53 times lower in families which had conflicts (Weaver et al., 2005).

Failing to adhere to treatment may occur due to many reasons. It may be due to patient-related factors such as lack of motivation or lack of knowledge. It may be contributed due to the nature of medication as medication may be perceived as having no effects or having side effects. Non-adherence may also be due to clinician factors such as lack of communication skills, failing to explain the treatment procedure clearly and about the impact of medication and how to consume it regularly (Jon & Sherry, 2005).

The patient may not usually report non-adherence to medication and also the clinician may not be aware of the patients' non-adherence. Non-adherence is a significant problem among the older group of patients who generally suffer from more than one health condition. In such cases, it may involve complex pharmacological treatment, which may be confusing and may be attributed to their tendency of forgetfulness (Gray et al., 2001).

A study conducted in India on patients with hypertension found that the condition was inadequately controlled, the main reason being non-adherence to anti-hypertensive medication. This was the main contributing factor to poor blood pressure levels, and the onset of cardiovascular diseases (Sasidharan et.al. 2011).

Poor adherence is a major obstacle in diabetes management and is a burden for the patients, their families and the health care system. In a study conducted on 152 randomly selected diabetes patients, it was found that 51.32% of the patients perceived that they could not afford the diabetes medication and of the total sample, 56.6% of the patients were above the age of 61 years. It was concluded that age, gender and affordability was a major factor in non-adherence (Awodele, & Osuolale, 2015).

A study conducted in Kerala, India found a significant relationship between age, and adherence behavior, the female gender and married population were seen to have higher adherence. The study also found that as the level of the education of the patients increased, there was an increase in their adherence behavior (Shaimol, Biju, Anilasree, Jayakrishnan, & Babu, 2014).

Adherence contributes to not just physical health but also mental health and overall well-being. It was found among HIV positive patients that those who adhered to treatment regimen had higher levels of self-efficacy, lower feelings of stigma, improved mental health, coping and overall QOL (Mo & Mak, 2009). However some studies have shown that there may not be a direct association between adherence and QOL. Adherence may indirectly impact QOL through glycemic control and having an overall positive attitude.

A study was conducted to assess the association between QOL and treatment adherence among Type II diabetes patients (Martinez, Prado-Aguilar, Rascon-Pacheco, & Valdivia-Martinez, 2008). This study which was an in-depth study conducted on 238 randomly selected patients found that there existed no relationship between treatment adherence and quality of life. However, the study found that strong knowledge about the disease and an optimistic attitude towards the disease contributed to overall well-being and QOL.

## Quality of life and diabetes

Diabetes being a life-long incurable illness becomes a part of one's daily life. The constant monitoring of one's health and the onus on the patient to maintain optimal glycemic control to avoid onset of any complications becomes a burden which cannot be redeemed. Such a constant burden, definitely takes a toll on one's quality of life and satisfaction in life. Studies have shown that diabetes patients have lower QOL than those who do not suffer from the disease (Aguiar et al., 2009). QOL of a patient is affected by one's age, gender, ethnicity, education level, knowledge of the disease and other psychological variables and the physical symptoms and complications (Edelman, Olsen, Dudley, Harris, & Oddone, 2002). A person's QOL is also affected by the social stigma, and about being labeled as a "diabetic". The condition not only affects the patient but also influences the family and social relationships (Zulian et al., 2013).

A comparative study done between Type II diabetes patients above 60 years and those between 30 -65 years found that those above 60 years reported physical limitations in their daily functioning but their social functioning seemed to be better. The study also found that those above 60 years showed high satisfaction with disease related aspects and better ability to cope with their condition than those of the lesser age group (Trief, Wade, Pine, & Weinstock, 2003).

However, a study conducted in India, on patients belonging to rural tertiary care found that as the diabetes patients' age increased there was a decrease in QOL. Also, fluctuation in glucose levels over a prolonged period of time also impacted QOL negatively (Somappa, Venkatesha, & Prasad, 2014). The gender of the patients also influences one's QOL. It was found that diabetic women have lower QOL than men. However, men reported to experience low QOL when the disease impacted their daily work and functioning and due to lack of insufficient time to manage their disease. In addition, those patients who have a co-morbid condition along with diabetes have higher health disturbance and greater strain in their QOL (Wändell, Brorsson, & Aberg, 2000).

Diabetes patients face greater difficulty not only when they suffer from a comorbid condition but also when they experience other psychological issues. Polonsky and Hessler (2013) found that perceived control was one of the major contributors of QOL. Higher the perceived control better was the QOL of the patients. Individual differences exist in the way individuals perceive and cope with every situation. Individual who possess low perceived control, assess the situation as more threatening and find it difficult to adjust and cope with it (Pallant, 2000). Depression and anxiety were found to be present in those patients who had relatively low perceived control (Hudson, Bundy, Coventry, & Dickens, 2014), which in turn led to high psychological distress (Mullins, Chaney, Hartman, & Domek, 2002).

The distress produced by diabetes management and the accompanying depression has predicted low quality of life among Type II diabetes patients (Carper et al., 2013). The study by Carper and colleagues also shows that positive coping strategies such as inculcating a sense of achievement, boosting one's self-worth, engaging in healthy social relationships and environment contributes to one's growth and improves the QOL of diabetes patients. The association between QOL and perceived control is to such an extent that perceived control impact both physical and psychological aspects of QOL (Hernandez-Tejada, Lynch, Strom, & Egede, 2012).

#### **Summary of Literature Review**

To summarize the literature that has been reviewed it can be said that diabetes is a condition wherein the impact of the disease on the patients is seen right from the stage of diagnosis. The diagnosis remains to be a traumatic event that the patient needs to cope with. The process of coping affects the manner in which the patients adjust to forthcoming changes that need to take place in terms of their lifestyle changes and adapting to treatment regimen. The clinicians play a prominent role in providing the patients with initial support, normalizing the situation and helping them appraise the situation in a less threatening manner. Clinicians also play an important role in equipping the patients with the required information and scientific knowledge about the disease. Patients' fundamental requirement after diagnosis is to receive support from family and friends and to gain knowledge about the condition. This is of prime importance as the newly diagnosed patients have to accommodate changes to their already established lifestyle and routine, all of a sudden. In addition, the treatment and management of diabetes is a relatively continuous process, as patients have to monitor their energy levels, regulate their intake of food, consume timely medication, monitor their blood glucose levels and keep up their fitness regimen. This continuous and rather tiring process of managing diabetes takes a toll on the patients not just physically, but psychologically, socially and financially.

Social support plays an important role in helping the patient adjust to the lifechanging events in their life. Social support plays an important throughout one's life, but especially during the first few years of diagnosis, it is very crucial. The literature review suggests the importance of knowledge about the disease and its role in helping the patients making the necessary changes. Many studies have supported the fact that knowledge helps in improving one's self-efficacy and adherence to treatment regimen. Studies have also shown how self-efficacy plays a major role in one's adherence and its impact on the most important outcome of the treatment—achieving good glycemic control. Adherence has a short-term and long-term effect on one's QOL. Studies have also shown that once the patients are able to get habituated to a healthy pattern of lifestyle which includes strict adherence to treatment regimen and lifestyle changes, their overall health improves with better glycemic control, improved energy levels and vitality which helps them to have a positive evaluation of their own life.

## Rationale

As mentioned, the chronic condition of diabetes is characterized by symptoms that one has to deal with everyday and also face the risk of suffering from diabetesrelated complications in the long run. In order to manage diabetes well, and reduce or delay the onset of complications, one has to adhere to a relatively strict treatment regimen and implement lifestyle changes. And having to deal with a life-long condition, the patient's quality of life is considerably affected. The constant worry of monitoring glucose levels, and adjusting their medication dosage or altering their diet takes a toll on their psychological and emotional well-being. In such a scenario, the patients do require their psychological and social resources in order to cope with the disease. After reviewing literature, it was understood that among many factors, social support, knowledge about diabetes and self-efficacy are few of the important ones in dealing with diabetes. Social support is one of the crucial elements, in the first year to deal with the diagnosis and in later stages to keep up one's adherence levels and support in dealing with the disease. The factor of knowledge equips the patient to understand the nature, causes of the disease and gives them information about managing it. However, possessing knowledge and support does not necessarily help diabetes patients in adhering to the treatment. Selfefficacy is one of the defining factors of adherence behavior, as the patients have to make rudimentary changes in their diet, physical activity, and be punctual with their medication and check-ups. The interest in conducting this study was to identify the factors that essentially play a role in adherence and quality of life of diabetes patients. The researcher was also curious if there would be a variation in the levels of these factors as one's duration of illness increases. Identifying the changing pattern of these variables would give an insight and pave a way in developing future interventions that would help patients who are in different stages of disease duration, to help them manage diabetes well and optimize their quality of life.

#### **Research Questions**

The main research questions of this study were:

- Does the duration of illness play a role in determining the level of knowledge, social support, self-efficacy, adherence, and quality of life?
- 2. Does there exist a relationship between knowledge, social support, selfefficacy, adherence, and quality of life of Type II diabetes patients?

3. Do knowledge, social support, and self-efficacy play a role in adherence and quality of life of Type II diabetes patients?

## **Objectives**

On the basis of the above research questions, following objectives were outlined:

- 1. To find out the difference in the level of knowledge, social support, selfefficacy, adherence, and quality of life among three groups of Type II diabetes patients categorized on the basis of duration of illness.
- 2. To find out the relationship between knowledge, social support, self-efficacy, adherence, and quality of life of Type II diabetes patients.
- 3. To assess the role of knowledge, social support, and self-efficacy in adherence and quality of life of Type II diabetes patients.

## Hypotheses

It was hypothesized that:

- 1. There would be a difference in the level of knowledge, social support, selfefficacy, adherence, and quality of life among three groups of Type II diabetes patients categorized on the basis of duration of illness.
- 2. There would be a relationship between knowledge, social support, selfefficacy, adherence, and quality of life of Type II diabetes patients.
- 3. Knowledge, social support, and self-efficacy would play a role in adherence and quality of life of Type II diabetes patients.

#### Chapter III

## Method

This chapter provides the plan, design, and sample of the present study; the detailed description of the research instruments that were used and the procedure that was followed to reach the objectives of the study.

#### **Plan and Design**

The objectives of the study were to find out if there would be a difference in the level of knowledge of diabetes, social support, self-efficacy, adherence and quality of life among Type II diabetes patients with different duration of disease and also to assess the impact of knowledge of diabetes, social support and self-efficacy on adherence and quality of life of Type II diabetes patients.

To meet these objectives, it was planned to approach hospitals and diabetic clinics providing treatment to those suffering from Type 2 diabetes. It was planned to select a hospital or clinic with an attached laboratory, which the patients frequent to in order to get their medical tests done and to check their glucose levels. This allowed the patients to complete the questionnaires. It was also planned to meet diabetic patients at their home according to their willingness.

The study used a correlational design with cross-sectional approach. The main study was conducted on diabetes patients, who were in the age range of 25- 75 years and who had been diagnosed with Type 2 diabetes. The main variables under study included knowledge of diabetes, social support, self-efficacy, and duration of disease which were considered as the predictor variables, while adherence and quality of life were considered as the criterion variables. And to find out the difference in the level of the variables under study, the total sample was divided into three groups: group I consisting of patients with duration of disease of one month- one year; group II consisting of those with duration of disease above 1 year-5 years; group III consisting of patients with duration of disease of more than 5 years- 20 years. The groups were compared to find out the changing pattern of the variables under study, as the duration of the disease increases.

## **Participants**

Purposive sampling method was used to gather data from 235 patients from two hospitals and four diabetic clinics for the main study. The sample characteristics are furnished in Table 1 and 2.

# Table 1

Demographic Details	Frequency	Percentage	
Gender			
Males	118	50.2	
Females	117	49.8	
Category of Disease Duration			
0-1 year	77	32.8	
1-5 years	79	33.6	
5 years-20 years	79	33.6	
Education			
Illiterate	24	10.1	
Primary	14	6.0	
Secondary	26	11.1	
High School	62	26.4	
Intermediate	30	12.8	
Graduation	45	19.1	
Post Graduation	34	14.5	
Occupation			
Unemployed	1	0.4	
Housewife	94	40.0	
Private/Government Employee	61	26.0	
Business	38	16.1	
Farmer	10	4.3	
Retired	21	8.9	

Table showing the demographic details of the total sample

Corporate Employee	10	4.3

Table 1 shows that the sample consisted of both men and women, who were within the age range of 25-75 years (M = 51.22, SD = 10.96). The range of disease duration of the sample was from one month to 20 years (M = 5.44, SD = 5.21). The sample consisted of participants who were illiterate (10.1%), and with varied educational level— primary (6%), secondary (11.1%), high school (26.4%), intermediate (12.8%), graduation (19.1%), and post graduation (14.5%). The sample was also found to consist of participants who were unemployed (0.4%), and those from various occupational backgrounds such as homemakers (40%), private or government employees (26%), entrepreneurs (16.1%), farmers (4.3%), retired persons (8.9%), and those working in corporate sector (4.3%).The total sample was divided into three groups based on the duration of the disease.

## Table 2

Table showing the range, mean and standard deviation of age and duration of disease of the total sample and of the three groups

	Min	Max	Range	M	SD
Total Sample					
Age	25	75	50	51.22	10.96
Duration of Disease	0.1	20.0	19.9	5.44	5.21
Group I					
Age	25	75	50	48.04	12.36

Duration of Disease	0.1	1.0	0.9	0.52	0.29
Group II					
Age	25	69	44	49.43	10.02
Duration of Disease	1.0	5.0	4.0	3.73	1.17
Group III					
Age	35	74	39	56.10	8.62
Duration of Disease	7.0	20.0	13.0	11.93	3.24

Group I consisted of 77 participants, which is 32.8% of the total sample with 44 men and 33 women, who were within the age range of 25-75 years (M = 48.04, SD =12.36). As seen in Table 2, the range of disease duration of group I was from one month to 1 year (M = .52, SD = .29). Group II consisted of 79 participants, which is 33.6% of the total sample with 42 men and 37 women, who were within the age range of 25-69 years (M = 49.43, SD = 10.02). The range of disease duration of group II was from 1 year to 5 years (M = 3.73, SD = 1.17). Group III also consisted of 79 participants, which is 33.6% of the total sample with 32 men and 47 women, who were within the age range of 35-74 years (M = 56.10, SD = 8.62). The range of disease duration of group III was from 7 year to 20 years (M = 11.93, SD = 3.23). Patients were selected from different hospitals and diabetic clinics in Hyderabad, where they consulted the diabetologist for regular checkups. Persons suffering from Type II diabetes for at least one month and between the age of 25-75 years, were included in the study. Both insulin and non-insulin dependent patients were included in the sample. Patients below the age of 25 and above the age of 75; who were suffering from co-morbid conditions like terminal illness, psychiatric illness, serious cardiac diseases, hepatic, thyroid disorders and whose duration of disease was within the timeframe of one month and exceeded 20 years were excluded.

#### **Research Instruments**

In order to gather data on the variables under study the following instruments were used: Clinical History Proforma, Diabetes Symptoms Checklist, The Diabetes Knowledge Test for Indian Population (DKT-I), Interpersonal Support Evaluation List (ISEL), Stanford Self-efficacy Scale for Diabetes, Diabetes Adherence Scale (DAS), and Diabetes-39 Quality of Life Questionnaire. The participants were required to complete the above mentioned instruments that contained items for assessing their knowledge about diabetes, social support, self-efficacy, adherence and quality of life. These questionnaires which were essentially in English were translated into Telugu by a native Telugu speaking bilingual person. The back-translations of these questionnaires were performed by another native Telugu-speaking bilingual person who had a Postgraduate degree in Psychology. The back-translations were compared with the original version of the questionnaires by another English speaking person. Participants who were comfortable with Telugu completed the Telugu version of the questionnaires. The detailed description of each instrument is given below.

**Clinical History Proforma.** A proforma was developed by the researcher specifically for the purpose of this study to find out the medical history of the patient. This elicits information about the age, gender, weight, date of diagnosis of current condition, nature of medication, diseases in the past, other co-morbid condition at present, family history of the current condition.

**Diabetes Symptoms Checklist.** This checklist was developed by the researcher for this study to assess the symptoms which the patient is experiencing on daily basis for a period of one week. The checklist consisted of 15 items, covered symptoms like frequent urination, thirst, blurred vision, irritability and other commonly occurring symptoms. The patient responded by rating the frequency of experiencing the symptom, by choosing from three options of 'never', which was given a score of '0', 'sometimes', given a score of '1' or 'often', given a score of '2'. The checklist also gave information about the number of symptoms experience. Out of the 15 items, the items marked as 'never' were excluded and the rest of them were counted as the number of symptoms experienced. The participants rated the symptoms they experienced on 3-point scale, with the following response category of 0 -never, 1 -sometimes, and 2 -often. The score ranges from 0-30, with 0-10 labeled as 'mild symptoms', 11-20 labeled as 'moderate symptoms', and 21-30 labeled as 'severe symptoms'. The observed internal consistency Cronbach's alpha value of the checklist based on the sample of this study was found to be .78.

#### The Diabetes Knowledge Test for Indian Population (DKT-I.) The DKT-I

(Padhy, Padiri, Harihararan & Rana, 2015) consisted of 37 items and aimed to assess the knowledge specific to diabetes on four dimensions such as 'symptoms' –9 items, 'causes and risk factors' –12 items, 'complications' –11 items, and 'management' –5 items. In each dimension, items related to different illnesses (e.g., difficulty in breathing, blood transfusion, chest pain, low fat diet) were also included along with those specific to diabetes. Items also included popular myths and misconceptions related to diabetes (e.g., joint pains, contact with diabetic people, headache, and avoidance of cold weather). To facilitate easy understanding of the items, simple and common language was used instead of medical terms pertaining to the four dimensions. The participants were to respond if each item was "true", or "false" with regard to diabetes. A score of 1 was given for each correct response (either true or false) and a score of 0 was given for any incorrect response. The lowest score and the highest score that could be obtained in on the overall test score was 0 and 37respectively. The reliability coefficient of the instrument which was calculated by using the Kuder-Richardson 20 ([KR-20] Kuder and Richardson 1937) was.76.

**Interpersonal Support Evaluation List (ISEL).** The scale was developed by Cohen and Hoberman (1983). Items were developed on theoretical grounds to cover the domain of supportive social resources that could potentially facilitate coping with stressful events. The scale consisted of 40 statements concerning the perceived availability of potential social resources, which fall into four 10-item subscales. The "tangible" subscale measured perceived availability of material aid; the "appraisal" subscale measured the perceived availability of someone to talk to about one's problems; the "self-esteem" subscale measured the perceived availability of a positive comparison when comparing one's self with others; and the "belonging" subscale measured the perceived availability of people one can do things with. The ISEL was used to assess the perceived availability of four separate functions of social support as well as providing an overall functional support measure. Therefore the scales are reasonably independent of one another. The items were counterbalanced for desirability that is half of the items were positive statements about social relationships while half were negative statements. Respondents were asked to indicate whether each statement is "definitely true" or

"probably true" or "probably false" or "definitely false" about themselves, a score of 3, 2, 1, and 0, was given respectively to each of these options. However 20 items were to be reverse scored. The items for each subscale were given in the manual, which has been appended. The score for each subscale was calculated by adding the score allocated to the response that was selected by the individual. Higher the score, higher is the perceived support by the individual on that particular subscale. The total ISEL score was obtained by adding the scores of all the subscales. The range of score for each subscale would be 0-30. Similarly the range for total ISEL score would be 0-120. Internal reliability (Alpha Coefficient) of the total general population ISEL as given by the developers range from .88 to .90 and for subscales it ranges from .70 to .82 for appraisal, .62-.73 for self-esteem, .73-.78 for belonging, and .73-.81 for tangible support. A six month test-retest correlations were .74 for the entire ISEL; .49 for the tangible subscale; .54 for the selfesteem; .68 for the belonging; and .60 for appraisal. The scales have been validated with other measures, and the correlation of ISEL general population scale with the Moos Family Environment Scale was found to be .30 (Moos & Moos, 1981). The desire for verbal intimacy subscale of the Colwill and Spinner Privacy Measure correlated .40 (p<.001) with the appraisal scale and .80 and .24 (p<.01) with the tangible and belonging scales respectively. The self-esteem support subscale from the ISEL was correlated .74 (p<.001) with the Rosenberg Self-esteem Scale (1965). The Cronbach's alpha value of the ISEL based on the sample of this study was found to be .87 for total ISEL, and for the dimensions of appraisal support-.89, tangible support-.79, belonging support-.59, and self-esteem support-.72.

Stanford Self-efficacy Scale for Diabetes. This scale was developed by Stanford Patient Education Research Center, funded by the National Institute of Nursing Research (NINR) in United States of America (Lorig, Ritter, Villa, & Armas, 2009). The scale consisted of eight items, which measured the confidence of the patients in doing certain diabetes related activities like managing their diet, exercising, monitoring their blood glucose levels, visiting the doctor and daily functioning. The respondent rated the response for each item by circling a number on a 10 point scale where a score of 1 indicates "not at all confident" and a score of 10 indicates "totally confident". The score for each item was the number which was circled. If two consecutive numbers were circled, the lower number was coded. If the numbers which were circled were not consecutive, the item was not scored. If more than two items were missing, the scale was not scored. The score for the scale was the mean of the six or eight items. The observed range of the score is 1-10. Higher score indicated higher self-efficacy. The internal consistency reliability was found to be .82, as given by the developers. The observed internal consistency Cronbach's alpha value of this scale based on the sample of this study was found to be .78.

**Diabetes Adherence Scale (DAS).** This scale has been adapted by the researcher from the original 14-item Hill Bone High Blood Pressure Compliance Scale (Kim, Hill, Bone,&Levine, 2000). The items of the original 14-item scale were modified to make them applicable to diabetes, for example, words like 'HBP medicine', 'salty foods' were replaced with words like 'medicine for diabetes', 'foods rich in sucrose or carbohydrate content'. Items number 7, 8, and 10 were dropped, and four new items were added to include items on blood glucose monitoring and exercise regimen of the patients. The

adapted version therefore, had 15 items. The DAS measures patient behaviors for five domains of adherence namely- reduced sucrose intake (diet), keeping doctor's appointment, taking medication, monitoring blood glucose level, and following exercise regime. The scale consisted of 15 items, each graded according to a five-point scale. The patient rated his/her response for each item by ticking on one of the five options of "None of the time"; "Some of the time"; "Most of the time"; "All the time"; "Not applicable/ Do not know", which were given a score of 4,3,2,1 and 0 respectively. Items numbered 6, 12 and 13 were reverse scored. The total score was calculated by adding the score of each item based on the response given by the subject and score allotted to the option. Higher the score better the adherence and the score can range from 0-60. Items number 7, 8, and 9 from the original scale have been omitted, and items 13, 14, and 15 have been added to the Diabetes Adherence Scale in order include items on exercise. The standardized alpha of the original scale for the total scale ranged between 0.74 and 0.84 and the average inter-item correlations were 0.18 and 0.28 respectively. The observed internal consistency Cronbach's alpha value of this adherence scale based on the sample of this study was found to be .71.

**Diabetes-39 Quality of Life Questionnaire (Diabetes-39 QOL).** The Diabetes-39 QOL (Boyer &Earp, 1997) is a 39-item instrument consisting of five domains – diabetes control, anxiety and worry, social burden, sexual functioning, and energy and mobility containing 12, 4, 5, 3, and 15 items respectively. Each scale evaluates a distinct dimension of health and reflects the physical, mental, social, and functional components of health that play a key role in assessment of patient's quality of life. Patients responded to the items on a seven point scale (numbered from 1 to 7). Depending upon where the cross is placed by the respondent the scores were given which range from 0.5 to 7.5. The items belonging to the particular scales were mentioned in the scoring instructions booklet. If in total more than 4 items were missing (excluding missing items in sexual function scale) the questionnaires were to be excluded from the analysis. No value was presented for scales when a certain number of items were missing. The raw score for each scale was calculated by adding the responses of individual items. The possible ranges of raw scores for the scales were: diabetes control 6-90; anxiety and worry 2-30; social burden 2.5-37.5; sexual functioning 1.5-22.5; and energy and mobility 7.5-112.5. Lower the raw score, greater the quality of life in that specific area. Raw scores were transformed to a 0-100 scale using a linear transformation for each scale i.e. [(Raw scale score – lowest possible score) / (highest possible score –lowest possible score)] x100. The convergent and discriminant validity was assessed; correlations between each item and its correlated scale score ranged from 0.45 to 0.84, each item had a stronger correlation with its corrected scale score than it did with any of the other five scale scores. Construct validity of Diabetes-39 was evaluated using the SF-36 Health Status Questionnaire; strong negative correlations were identified. Strong negative correlations were also observed between the five scales of the Diabetes-39 and the global quality-oflife item. Internal reliability was determined by the developers using the Cronbach's coefficient alpha which ranged from 0.82 to 0.93. The observed internal consistency Cronbach's alpha value of the diabetes QOL questionnaire based on the sample of this study was found to be .92 for total questionnaire, and for the dimensions of diabetes control-.85, anxiety worry-.78, social burden-.76, sexual functioning- .89, and energy mobility-.84.

# Procedure

The course of conducting this study was extensive and elaborate. Initially, the variables under study were limited only to social support, self-efficacy, adherence and quality of life. After the initial finalization of the variables, the appropriate and standardized tools measuring the variables mentioned above were obtained. The ISEL measuring social support, and the Stanford self-efficacy scale for diabetes were readily available from secondary sources available online. The DAS was adapted from Hill Bone High Blood Pressure Compliance Scale (Kim, Hill, Bone and Levine 2000) by consulting medical experts and health psychologists in order to frame suitable items to measure adherence among diabetes patients. The information regarding the items which have been modified, and deleted from the original scale as well as those items which were newly added has been furnished in the tool description. To obtain the Diabetes-39 quality of life questionnaire, the researcher had corresponded with the developers of the instrument to obtain the questionnaire and its scoring manual.

After obtaining these instruments, it was considered necessary to frame a proforma to gather information about the clinical history of the patients. After reviewing the existing clinical history proformas, the researcher framed a comprehensive and customized proforma to elicit all the necessary details of the patients, which were considered to be important for this study. The description of the proforma has already been furnished in this chapter. Similarly, a symptom checklist was also developed to find out the frequency of symptoms that the patients suffer from. The checklist was developed by referring to the existing literature on common diabetes symptoms that the patients suffer from. The checklist was given developed with the inputs from diabetologists and

health psychologists and was administered in Phase I to verify its usability and readability.

Following the procurement and development of the necessary instruments, the ethics committee of the institute of University of Hyderabad was approached and the proposal to conduct this study was submitted. A panel of experts which included doctors and researchers from the field of Life sciences and Social Sciences reviewed the proposal and granted the permission to conduct the study.

The instruments selected for the study was then translated into the regional language Telugu, paying attention to use a balanced combination of simple and colloquial terms to aid easy understanding of the participants. The translated versions of the questionnaires were verified by language and subject experts, which were then back translated into English to ensure the replication of the original instruments. The Telugu versions of the instruments were then typed to utilize them for the study.

The study was conducted in two phases: Phase I –Pilot study and Phase II –Main study.

#### Phase –I Pilot Study

The pilot study was conducted to check the feasibility of the tools, feasibility of collecting data, the response of the participants and also to establish reliability of the instruments for the sample under study.

Initially few hospitals and diabetic clinics providing treatment to those suffering from Type II diabetes in the city of Hyderabad were identified, and permission was sought from the hospitals authorities to conduct the study. As mentioned earlier, it was planned to select a hospital or clinic with an attached laboratory, which the patients frequent to in order to get their medical tests done and to check their glucose levels. This was considered to be an important factor in selecting the clinics as it allowed the researcher to find more time to interact with the patients when they come to the laboratory and spend a couple of hours there. This allowed the patients to complete the questionnaires. It was also planned to meet diabetic patients at their home according to their willingness. Permission to conduct the study was granted by two hospitals and four diabetic clinics. After which regular visits were made to the hospitals on a regular basis to meet the patients.

The data were collected from 113 Type II diabetes patients, 57 men and 56 women, who were within the age range of 25-82 years (M = 51.34, SD = 11.91). The range of disease duration of the sample was from one week to 30 years (M = 7.61, SD = 6.22). The sample was categorized into four groups based on duration of disease. Group I consisted on patients from one week to one year duration of disease, Group II consisted of patients above one year to five years of duration, Group III consisted of patients from five years of duration and Group IV consisted of patients above 10 to 30 years of duration of disease. Persons suffering from Type II diabetes for at least one week and between the age range of 25-85 years were included in the study. Patients below the age of 25 and above the age of 85; who are suffering from co-morbid conditions like terminal illness, psychiatric illness, serious cardiac diseases, hepatic, thyroid disorders and whose duration of disease was within the timeframe of one week and exceeded 30 years were excluded.

The researcher approached the patients waiting in the out-patients units of the hospital or clinic and engaged in conversation to find out if they meet the inclusion criteria set for the study. After making sure that the patient met the inclusion criteria and belonged to one of the groups based on the duration of the disease, rapport was established, and the nature and purpose of the study was briefly communicated to them.

Following this, the patients would be ushered to a cabin attached to the laboratory, and were made to seat comfortably, ensuring them the privacy in order to read and answer the questionnaire without any intrusion. An informed consent form framed specifically for this study was handed over to the patients. Patients were given assurance about the confidentiality of their clinical information, responses to the questionnaires and about the usage of the collected data.

Following this, if the patient agreed to participate, they were requested to sign the consent form. The questionnaires were then administered one by one and instructions were given in Telugu or English in the language that they were comfortable with. Patients were encouraged to honestly answer to each question/item as suitable to their condition and experience and that there was no right or wrong answer. Any doubts regarding the items were clarified immediately. In order to avoid fatigue and error in measurement, the questionnaires were administered in two sessions. The patients would either opt to schedule the second session of administration after getting their lab reports and consultation with the doctor which would give a time gap of two to three hours between the two sessions or opt to come back the following day. This was done according to the convenience of the patients. After the patients finished filling up the questionnaires, they were debriefed in detail about the relevance of the study and a brief introspective report

of the patient's experience of participating in the study was noted down. In this manner data were gathered from the total sample, ensuring there were equal numbers of patients belonging to each group categorized based on different duration of disease.

After the data were collected, the scores of all the scales and questionnaires were calculated and entered systematically in to the Statistical package for Social Sciences (SPSS) software (Version 20.0) which was also used to analyze the data by computing descriptive statistics (Mean and Standard deviation) and inferential statistics (One Way Analysis of Variance, Tukey's HSD, Eta Squared, Pearson's Product Moment Correlation (r), Multiple Linear Regression, and Path analysis.

From the analysis of the pilot data, the feasibility of using the instruments and conducting the study was established. The reliability of each instrument based on the sample of the study was also established. The results of the pilot data showed significant correlations between the variables and the impact of the predictor variables such as social support and self-efficacy on the criterion variables of adherence and quality of life. However, no significant difference in the level of the variables was found between the four groups which were categorized based on duration of disease. Therefore it was recommended to limit the age range from 25-75 years and also to divide the sample into three groups (Group I- one month-1 year; Group II- 1 year to 5 years and Group III- 5 years and above) rather than four groups.

It was also recommended by subject experts to assess the patients' knowledge of diabetes, to find out if knowledge of diabetes played a role in their adherence to treatment and overall quality of life. Based on this suggestion, a new research objective was added to the study and the need to develop a new instrument arose as the existing instruments

measuring knowledge of diabetes were deemed to be unsuitable for the sample of the study.

#### Development of the Diabetes Knowledge Test for Indian Population

The development of this new instrument was done through four phases— Phase I: Item writing, Phase II: Content validation, Phase III: Item analysis and establishing reliability, and Phase IV: Establishing validity and developing norm.

## Phase I: Item writing

Along with existing literature on different instruments measuring knowledge of diabetes like the Diabetes Mellitus Knowledge ([DKN-A] Torres, Virginia and Schall 2005); the Diabetes Knowledge Assessment (DKN) scale (Dunn et al. 1984); the Revised Diabetes Knowledge Scale (Collins, Mughal, Barnett, Fitzgerald and Lloyd 2011); the Diabetic Numeracy Test (DNT) (Huizinga et al. 2008); the Diabetic Knowledge Questionnaire (DKQ) (Garcia, Villagomez, Brown, Kouzekanani and Hanis 2001); and Michigan Diabetes Knowledge Test (MDKT) (Fitzgerald et al. 1998) were referred. All these instruments were developed in the United States, United Kingdom, and Australia. Most of the existing instruments though widely used have certain limitations. For example, the Diabetes Mellitus Knowledge ([DKN-A] Torres, Virginia and Schall 2005) is a 40-item instrument, along with the 15-item parallel forms (DKNa, DKNb, and DKNc), contains long statements with multiple-choice response format. These instruments also contain terms such as 'protein', 'carbohydrates', items testing knowledge about 'one metric unit of energy', items testing if '5 oz milk is equal to 5 oz orange juice' are difficult for comprehension given the Indian scenario.

In addition, experts such as physicians, diabetologists, and health psychologists were consulted. The researcher also interacted and interviewed with 15 patients from different hospitals under study. Basing upon these resources initially 80 items pertaining to knowledge of diabetes were written in statement format, categorized into four dimensions such as symptoms, causes and risk factors, complications, and management. These items were to be responded by choosing the options of 'true' or 'false'. These items were given to three health psychologists and five diabetologists to assess the technicality of the items. It was suggested by the experts to use short phrases instead of statements. After converting the items to phrases, these were administered on a clinical sample of 10 persons with Type II diabetes for readability. Basing upon their comments the use of jargons, complex words, and ambiguity in the items were eliminated. Any duplication or overlapping items across the dimensions of the test were removed. At the completion of the first phase of item writing and review process, the test consisted of 64 items, categorized into four dimensions with 16 items in each dimension.

## Phase II: Content validation

To review whether the items of the test covered all the areas pertaining to knowledge of diabetes, it was given to a panel of eight doctors which included four diabetologists and four physicians. The experts were asked to review each of the items of the test and decide whether the item was 'essential' or 'not essential' in order to measure knowledge about diabetes. Items which were considered as essential by all the eight experts were included. That is, those items with 100% agreement of the experts were taken as the criterion to include the items. According to the experts review, 58 items were retained—Symptoms (13 items), Causes and risk factors (14 items), Complications (16 items), and Management (15 items). Following this screening of the items, expert opinion was sought from two diabetologists and 12 items were selected for each of the dimensions of symptoms, causes and risk factors, complications, and management and finalized for the testing of the developed measure.

It was planned to administer the newly developed test to persons suffering from Type 2 diabetes, in order to conduct item analysis, measure its reliability and validate it as a preliminary step in development of this instrument. Since this scale was meant for the persons suffering from Type II diabetes in India, the scale was named as Diabetes Knowledge Test for Indian Population and abbreviated as DKT-I. Two more phases were followed to standardize DKT-I –Phase III involved item analysis and establishing reliability whereas Phase IV involved measuring the validity and development of the norms.

#### *Phase III: Item analysis and reliability*

In Phase III the newly developed DKT-I was administered on a clinical sample of Type 2 diabetes. Item analysis was done basing on two criteria- item—difficulty index and item-discrimination index. Since the response of each of the item of DKT-I is dichotomous (true or false), Kuder-Richardson 20 (KR- 20) formula was applied to find out the reliability coefficient of DKT-I.

#### Method

# **Participants**

Purposive sampling method was used to select 250 Type II diabetes patients for the administration of DKT-I from out-patient units of two hospitals and four diabetic clinics in Hyderabad. Out of 250 participants data of 212 participants were retained because of withdrawal of participation by the patients and missing data. The sample comprised of both men and women, between the age range of 25- 75 years (M = 51.86, SD = 10.51). The range of disease duration of the sample was from one month to 20 years (M = 5.65, SD = 5.32). Persons suffering from Type II diabetes for at least one month and between the age range of 25-75 years were included in the study. Patients below the age of 25 and above the age of 75; who are suffering from co-morbid conditions like terminal illness, psychiatric illness, serious cardiac diseases, hepatic, thyroid disorders and whose duration of disease was within the timeframe of one month and exceeded 20 years were excluded.

### Brief description of the Diabetes Knowledge Test for Indian Population (DKT-I)

The DKT-I aimed to measure knowledge specific to diabetes mellitus. The test initially consisted of 48 items where each item has dichotomous response category— 'true' or 'false' (Appendix A1). The DKT-I comprised of four theoretical dimensions— Symptoms (e.g. frequent hunger), Causes and risk factors (e.g. lack of physical activity), Complications (e.g. kidney failure), and Management (e.g. reduced consumption of rice). Each dimension consisted of 12 items.

*Scoring of DKT-I*. A score of 1 is assigned for each correct response (either true or false) and a score of 0 for any incorrect response. Out of 48 items, all the items except items number 1, 4, 8, 10, 16, 17, 18, 21, 22, 24, 25, 28, 31, 32, 36, 38, 42, and 46 are given a score of 1 when the answer is 'false' and for the rest of the items a score of 1 is given when the answer is 'true'. The total score of the test varied from 0-48, whereas the total score for each dimension varied between 0 to12. Higher the score in a particular dimension, implies higher is the knowledge. Similarly higher the score on the total test, higher is the person's knowledge of diabetes mellitus.

The same procedure as the pilot study was followed to collect the data for this phase of tool development. And it took approximately 10-15 minutes to complete the DKT-I, after which the participants were debriefed.

## Item analysis

The obtained quantitative data were analyzed by using IBM SPSS Statistics 20 for item analysis and reliability. Two methods were used for item analysis—(i) itemdifficulty value (p), and (ii) item-discrimination value (d). These values were taken as criteria to identify relevant items for the test.

#### *Item-difficulty value*

The formula adopted to calculate the item-difficulty value (Crocker and Algina 1986) is:  $p=N_p/N$ ; where N<sub>p</sub> indicated the number of test takers in the total group who answered the item correctly and N denoted the total number of test takers in the group.

On the basis of the formula the item-difficulty value (*p*) was calculated for each item of the test

According to Lord (1952), the ideal difficulty level for multiple-choice items involving dichotomous response category is .85, i.e. those items with difficulty value above .85 are considered 'easy' and those below .15 are considered very difficult for the respondents to answer correctly. As the DKT-I was not a classroom test or a test that was assessing knowledge acquired from prior instruction or training, the cut-off range for the item-difficulty level was determined to be .10 to .90. This was considered to be so, as the knowledge of diabetes patients was being tested based on what they acquired from the doctors, family, friends, or from other patients and not from direct instructions or training.

Based on the decided cut-off range of .10 to .90, item number 37, 40, 41, 42, 43, 47, and 48 were dropped, reducing the 48 original items to 41 items with 12 items each in the dimension of symptoms, causes and risk factors and complications, and 5 items in the dimension of management.

## Item-discrimination value

This discrimination value (*d*) was calculated for each item by identifying 27% top scorers and 27% bottom scorers (Kelley 1939). The formula to calculate the itemdiscrimination value was:  $d = U_p - L_p / U$ ; where  $U_p$  and  $L_p$  indicates the number of respondents in the upper and lower groups who pass the item and U is the total number of respondents in the upper group. Using the formula, the discrimination values were calculated for all the items of the test. Higher the discrimination values of an item, the better the item's discriminating power.

According to Ebel and Frisbie (1986), items with discrimination value of .40 and above are considered to be 'good' items, those with .30 to .39 as 'reasonably good' items, those with .20 to .29 as 'marginal', and those below .19 as 'poor' items needing revision. As the test is not a classroom test, discriminating the merit of students but assessing the knowledge of the clinical population, the cut-off range for the discrimination value was taken as .10 to 1.0 considering the necessity of the items that measured the indicators of the disease. Based on this exclusive cut-off range of discrimination value, items number 1, 8, 10, and 28 were dropped. Items number 37, 41, 42, and 47 which were already dropped based on the cut-off range of item-difficulty value, were also found to have very low discrimination value. Thus the process of item analysis gave rise to 37 items of DKT-I showing variation of number of items in the dimensions—Symptoms (9 items), Causes and risk factors (12 items), Complications (11 items), and Management (5 items).

# Reliability

It was intended to measure the reliability of the test to determine the internal consistency of the test to examine whether the items of the test measure the same construct. To meet this end, it was decided to calculate the reliability coefficient by using the Kuder-Richardson 20 ([KR-20] Kuder and Richardson 1937), as response category of each of the items was dichotomous and difficulty value varied from .20 to .90. The

reliability coefficient was found to be .76. Hence this 37-item DKT-I was accepted for establishing validity and developing preliminary norm which was done with a new clinical sample under Phase IV of the study.

### Phase IV: Establishing validity and development of norm

Having conducted the item-analysis of the new test and establishing the reliability convergent validity of the DKT-I was established on a new group of clinical sample by identifying relevant constructs—adherence, self-efficacy, and social support. This sample group was the same on which the main study was conducted.

#### **Participants**

For establishing validity and norm of DKT-I, data were gathered from 300 patients suffering with Type II diabetes using purposive sampling method. Due to reasons such as missing data, and withdrawal by the participants, data gathered from 268 patients were taken into consideration. The sample for the validation of the test consisted of 136 male and 132 female patients, between the age of 25-75 years (M= 51.84, SD= 10.97). The range of duration of disease of the sample was found to be from 1 month to 35 years (M= 6.48, SD= 6.42). Persons suffering from Type II diabetes for at least one month and between the age of 25 and above the age of 75; who are suffering from co-morbid conditions like terminal illness, psychiatric illness, serious cardiac diseases, hepatic, thyroid disorders and whose duration of disease was within the timeframe of one month and exceeded 35 years were excluded.

To measure the criterion constructs the following instruments were used— Interpersonal Support Evaluation List (ISEL), Stanford Self-efficacy Scale for Diabetes, and Diabetes Adherence Scale, in addition to the newly developed DKT-I, whose description has been mentioned earlier in this chapter. The data was collected in the same procedure as the pilot study.

## Establishing Validity

Product-moment correlation coefficients were conducted in order to analyze and compare the relationship between the constructs and thereby establish the validity.

## Relationship between Diabetes Knowledge and Adherence

Results revealed that there was a significant positive correlation between different dimensions of knowledge of diabetes and adherence. The dimension of adherence to medicine was found to have a significant positive correlation with knowledge of management, r(266) = .13, p < .05. Adherence to diet was found to have a significant positive correlation with knowledge of symptoms, r(266) = .15, p < .05; and with knowledge of management, r(266) = .12, p < .05.

The dimension of adherence to exercise was found to have a significant positive relationship with all dimension of knowledge of diabetes: knowledge of symptoms, r(266)=.17, p<.01; knowledge of causes and risk factors, r(266)=.21, p<.01; knowledge of complications, r(266)=.22, p<.01; knowledge of management, r(266)=.12, p<.01; and the total knowledge related to diabetes, r(266)=.26, p<.01.

The dimension of adherence to blood glucose monitoring was found to have significant positive correlation with the dimension of knowledge of causes and risk factors, r(266)=.16, p<.05; and with total knowledge of diabetes, r(266)=.14, p<.05.

A significant positive correlation was found between total adherence and all dimensions of knowledge related to diabetes except for the dimension of knowledge of causes and risk factors. Adherence total was found to be correlated with the dimension of knowledge of symptoms, r(266)=.22, p<.0; with dimension of knowledge of complications, r(266)=.17, p<.01; with dimension of knowledge of management, r(266)=.19, p<.01; and with total knowledge of diabetes, r(266)=.22, p<.01.

The only significant negative correlation was found to be between the dimension of adherence to doctor's consultation and knowledge of causes and risk factors, r(266)= - .14, p< .05.

## Relationship between Diabetes Knowledge and Self-efficacy

Self-efficacy was found to have significant positive correlation with all dimensions of knowledge of diabetes namely knowledge of symptoms, r(266)=.30, p<.01; knowledge of causes and risk factors, r(266)=.36, p<.01; knowledge of complications, r(266)=.30, p<.01; knowledge of management, r(266)=.28, p<.01; and with the total knowledge of diabetes at r(266)=.43, p<.01.

## Relationship between Diabetes Knowledge and Social Support

There was a significant positive correlation between the two constructs on few dimensions. The dimension of appraisal support was found to have significant positive correlation with knowledge of causes and risk factors, r(266) = .15, p < .05; also with the dimension of knowledge of complications, r(266) = .14, p < .05, and with the total knowledge of diabetes at r(266) = .16, p < .05

Significant positive correlation was also found between the total social support and the dimension of knowledge of causes and risk factors, r(266)=.15, p<.05; with the dimension of knowledge of complication, r(266)=.12, p<.05; and with the total knowledge of diabetes r(266)=.14, p<.05.

However there was no significant correlation found between knowledge of diabetes and other dimension of social support, which were tangible support, belongingness support and self-esteem support.

Therefore it can be observed from the results that knowledge of diabetes has a strong and significant correlation with the constructs on self-efficacy and adherence. Persons having knowledge about diabetes symptoms, causes and risk factors, complications and management tend to have better/greater self-efficacy and show better adherence on the whole and specifically to exercise. Persons with better knowledge of symptoms have better adherence to diet, those with better knowledge of diabetes causes and risk factors have better adherence to blood glucose monitoring and lower adherence to keeping appointment with their doctor, those with better knowledge of diabetes management are shown to have better adherence to medication and diet, and those with over all knowledge of diabetes has shown to have better adherence to blood glucose monitoring.

Likewise, knowledge about causes and risk factors and complications of diabetes was found to have significant positive correlation with total social support and specifically with the dimension of appraisal support. In other words those having better social support and appraisal support in specific have better knowledge about diabetes causes, risk factors and complications. No correlation was found between other dimensions of knowledge of diabetes and social support.

These results helped in validating the newly developed measure DKT-I with the significant relationship that it was found to have with self-efficacy, adherence, appraisal support and overall social support. These findings are validated with the help of previous literature which found similar results and relationship among the constructs.

## Development of norm

Another task of this phase of developing the DKT-I was to develop the preliminary norm for the clinical population in India. Statistical analysis such as M, SD, and percentile scores were done to develop norm for the total sample. The independent t-test results revealed that there was a significant difference between male and female patients in respect of knowledge of diabetes, t(266)=3.58, p<.001, indicating male patients have higher knowledge (M=25.76, SD=4.61) than female patients (M=23.52, SD=5.61). For this, gender-based norm was developed not only for the overall knowledge, but also for each of the four dimensions.

Results revealed that the mean score of the total sample on DKT-I total was found to be (M=24.65, SD=5.24), dimensions of Symptoms (M=7.11, SD=1.77), Causes and risk factors (M=7.09, SD= 2.37), Complications (M=7.18, SD= 1.92), and Management (M=3.27, SD= 0.96). The 95% confidence interval was also calculated.

The norm was calculated for overall knowledge and dimension specific knowledge in respect to the total sample and each gender. The range of the low score was determined by subtracting 1 *SD* from the *M* (*M*- 1 *SD*), whereas the high score was calculated by adding 1 *SD* to the *M* (*M* + 1 *SD*). The norm has been developed by classifying the range of scores under three categories—high, average, and low. When the patients score was within the range of 29.89 to 37.00 in overall knowledge, they are expected to have high level of knowledge. Likewise, if the patients score within the range of 0 to 19.40 they are expected to have low knowledge, whereas those who score between 19.41to 29.88 are expected to have average knowledge in diabetes mellitus. Likewise, the interpretation of the norm is to be done for each dimension and gender.

In this manner the new instrument suitable for Indian clinical population was developed, its psychometric properties evaluation and gender-based norm established. The data for the main study was collected simultaneous along with the data collected for the validation of the DKT-I.

#### **Phase-II Main Study**

The procedure for the main study was similar to the phase I –pilot study. The same hospitals and clinics that were visited for the pilot study were frequented by the researcher to gather the data. The main study differed from the pilot study only in the aspect of inclusion and exclusion criteria –age limit of the participants and the categorization of groups based on duration of disease. The age limit of the participants

for the main study was limited from 25 years to 75 years and the sample was categorized into three groups instead of four, group I consisted of patients from one month to one year duration of disease, group II consisted of patients above one to five years of duration of disease and group III consisted of those within the range of above 5 years to 20 years of duration of disease.

The researcher identified participants, built rapport with them and obtained their consent to participate, after which they were asked to fill in the questionnaires in to two sessions of administration either on the same day with a time gap or the following day. The participants were debriefed about the research work and their introspective report was taken following the administration of the questionnaires. The data were gathered in this manner and the questionnaires were scored and entered into the SPSS for further analysis.

### **Data Analysis**

The data were analyzed using the Statistical package for Social Sciences (SPSS) software (Version 20.0) to compute descriptive statistics (Mean and Standard deviation) and inferential statistics (One Way Analysis of Variance, Tukey's HSD, Eta Squared, Pearson's Product Moment Correlation (*r*), Multiple Linear Regression, and Path analysis.

#### Chapter IV

This chapter describes the results obtained from the in-depth analysis of the data that were gathered for the study. The data were analyzed using IBM SPSS Statistics 20. The results analyzed the level of knowledge of diabetes, social support, self-efficacy, adherence and quality of life among Type II diabetes patients with different duration of disease. Here the duration of disease was considered as the independent variable and the dependent variables were knowledge of diabetes (dimensions namely symptoms, causes, complications and management), social support (dimensions of appraisal support, tangible support, belongingness support, and self-esteem support), self-efficacy, adherence (dimensions of medicine, diet, exercise, exercise, blood glucose monitoring, and doctor's consultation), and quality of life (dimensions of diabetes control, anxiety and worry, social burden, sexual functioning, and energy and mobility). In order to find out the empirical evidence for this objective, the data were analyzed using descriptive statistics (Mean and Standard deviation) and inferential statistics (One-Way Analysis of Variance and Tukey's HSD). Further analysis was done to find out the correlation between the variables under study and to assess the impact of the predictor variables namely knowledge of diabetes, social support, and self-efficacy on the criterion variables namely adherence and quality of life. The empirical evidence for this objective was found out by analyzing the data using inferential statistics such as Pearson's product moment correlation (r), and multiple linear regression. Subsequently, an attempt was made to investigate the pathway between the predictor and the criterion variables. The chapter explains in detail the results obtained from the analysis.

The level of symptoms, knowledge of diabetes, social support, self-efficacy, adherence and quality of life among Type II diabetes patients with different duration of disease

The sample consisted of three groups of diabetes patients belonging to the different disease duration. Group I consisted of diabetes patients whose duration of disease was less than 1 year, group II consisted of diabetes patients who were above 1 year-5 years of duration of disease, group III consisted of those diabetes patients whose duration of disease was 5 years and above.

Table 3 describes the mean scores (M), standard deviation (SD) and summary of one way ANOVA for symptoms experienced by the patients and the variables namely knowledge of diabetes, social support, self-efficacy, adherence and quality of life among the three groups.

Table 3 *Table sh* 

Table showing Mean, Standard deviation and summary of one-way ANOVA for the three groups.	
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	Gro	oup I	Gro	up II	Gro	up III	On	e-way AN(	OVA	
Duration of disease	( <b>n=77</b> )		( <b>n=79</b> )		( <b>n=79</b> )		Ι	Eta- Squared		
Variables	М	SD	М	SD	М	SD	Between	Error	F (2,232)	-
Knowledge of Diabetes	22.91	5.07	25.91	4.49	24.82	5.39	179.79	24.99	7.19**	.06
Symptoms	6.43	1.72	7.66	1.40	7.20	1.99	30.08	2.96	10.15***	.08
Causes	6.78	2.39	7.35	2.14	7.01	2.39	6.54	5.35	1.22	.01
Complications	6.71	1.78	7.57	1.72	7.13	2.08	14.28	3.48	4.10*	.03
Management	2.99	.98	3.33	.93	3.48	.89	4.98	.87	5.71**	.05
Social Support (SS)	94.23	10.90	90.80	14.04	91.58	13.82	251.99	169.39	1.49	.01
SS-Appraisal	22.71	6.78	20.67	9.15	21.44	8.81	82.88	69.28	1.19	.01
SS-Tangible	22.57	4.13	21.11	5.55	21.59	5.18	42.91	24.95	1.72	.02
SS-Belonging	23.26	2.48	22.76	2.73	22.77	2.55	6.32	6.72	.94	.01
SS-Self-esteem	25.69	1.75	26.25	2.27	25.77	2.67	7.29	5.13	1.42	.01
Self-efficacy	52.96	8.68	57.37	11.15	60.48	8.91	1111.92	93.16	11.94***	.09
Adherence (Adh)	51.42	4.84	52.52	4.79	52.61	4.06	34.25	20.89	1.64	.01
Adh-Medicine	26.45	1.59	27.19	1.79	27.38	1.34	18.56	2.52	7.37**	.06
Adh-Diet	10.83	1.140	11.19	1.051	11.28	.75	4.36	.99	4.42*	.04

Adh-Exercise	8.30	3.42	8.18	3.66	8.05	3.65	1.20	12.79	.09	.01
Adh-BGM	2.18	.72	2.13	.49	2.15	.43	.06	.31	.19	.02
Adh-D Consultation	3.65	.70	3.84	.57	3.75	.65	.68	.41	1.64	.01
Quality of Life (QOL)	97.04	50.19	85.00	39.06	89.09	50.48	2918.01	2194.80	1.33	.01
QOL-Diabetes Control	18.68	11.59	16.35	9.89	16.67	9.81	123.66	109.32	1.13	.01
QOL-Anxiety Worry	30.01	19.19	26.63	19.22	24.23	19.09	656.31	367.45	1.79	.02
QOL-Social Burden	15.64	13.23	11.05	7.64	9.78	6.29	738.09	90.28	8.18***	.07
QOL-Sex Functioning	16.17	13.57	16.43	14.49	20.34	21.98	429.91	293.31	1.47	.01
QOL-Energy Mobility	16.54	8.83	14.54	7.073	18.07	12.16	246.20	92.04	2.68	.02

*Note.* Group I – One month –1year, Group II – 1-5 years, Group III – Above 5 years – 20 years p<0.05, p<0.01, p<0.01, p<0.01

# Table 4

Table showing mean comparisons using Tukey's HSD between the three groups of duration of disease of the variables under study

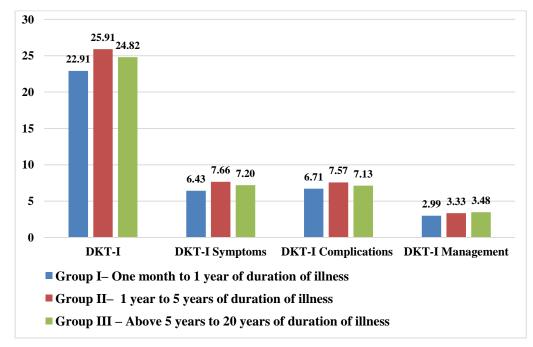
Variables	Duration of disease								
, and the second s	Group I- Group II	Group I-Group III	Group II- Group III						
Knowledge of Diabetes	-3.01**	-1.91*	1.09						
Symptoms	-1.23***	77*	.46						
Causes	58	23	.34						
Complications	86*	41	.44						
Management	34	49**	15						
Social Support (SS)	3.44	2.65	79						
SS – Appraisal	2.04	1.27	77						
SS – Tangible	1.46	.98	48						
SS – Belonging	.50	.49	01						
SS – Self-esteem	57	08	.48						
Self-efficacy	-4.41*	-7.52***	-3.11						
Adherence (Adh)	-1.10	-1.19	09						
Adh – Medicine	74*	93**	19						
Adh – Diet	36	45*	09						
Adh – Exercise	.12	.25	.13						
Adh-BGM	.06	.03	03						
Adh – Doctor's consultation	19	09	.09						
Quality of Life (QOL)	12.04	7.95	-4.09						

		• • • •	
QOL – Diabetes Control	2.33	2.01	32
QOL – Anxiety and Worry	3.38	5.78	2.39
QOL – Social Burden	4.59**	5.86***	1.27
QOL – Sexual Functioning	25	-4.17	-3.92
QOL – Energy and Mobility	1.99	-1.52	-3.52

*Note*. Group I – One month –1year, Group II – 1-5 years, Group III – Above 5 years – 20 years p<0.05, p<0.01, p<0.01

# Figure 1

Figure showing the mean values of the three groups on knowledge of diabetes and three of its dimensions





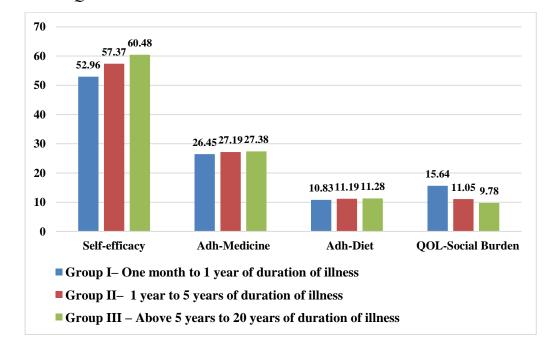


Figure showing the mean values of the three groups on self-efficacy, dimensions of adherence and OOL

#### **Knowledge of diabetes**

The results of one-way ANOVA presented in Table 3 revealed a statistically significant difference between the three groups in their knowledge of diabetes, F (2,232) = 7.19, p<0.01. The  $\eta^2$  was found to be 0.06 stating that the influence of duration of disease on knowledge of diabetes is medium. The Tukey's HSD score presented in Table 4 indicated a statistically significant difference between group I (M=22.91, SD=5.07) and group II (M=25.91, SD=4.49) in their knowledge of diabetes (MD=3.01, p<0.01). Group I (M=22.91, SD=5.07) was found to be significantly different from group III (M=24.82, SD=5.39) in their knowledge of diabetes (MD=1.91, p<0.05). Whereas, no significant difference was found between group II and group III. Likewise, the three groups also differed significantly on the dimensions of knowledge of diabetes.

## Knowledge of diabetes symptoms

A statistically significant difference was found between the three groups in their knowledge of diabetes symptoms, F(2,232) = 10.15, p < 0.001. The  $\eta^2$  was found to be 0.08 stating that the influence of duration of disease on knowledge of diabetes symptoms is medium. The Tukey's HSD score presented in Table 4indicated a statistically significant difference between group I (M=6.43, SD=1.72) and group II (M=7.66, SD=1.40) in their knowledge of diabetes symptoms (MD=1.23, p<0.001). Group I (M=6.43, SD=1.72) was found to be significantly different from group III (M=7.20, SD=1.99) in their knowledge of diabetes symptoms (MD=.77, p<0.05). Whereas, no significant difference was found between group II and group III.

## Knowledge of diabetes causes

There was no statistically significant difference between the three groups in their knowledge of diabetes causes.

## Knowledge of diabetes complications

A statistically significant difference was found between the three groups in their knowledge of diabetes complications, F(2,232) = 4.10, p < 0.05. The  $\eta^2$  was found to be 0.03 stating that the influence of duration of disease on knowledge of diabetes complications is small. The Tukey's HSD score presented in Table 4 indicated a statistically significant difference between group I (M=6.71, SD=1.78) and group II (M=7.57, SD=1.72) in their knowledge of diabetes complications (MD=.86, p < 0.05). Whereas, no significant difference was found between group I and group III and also between group II and group III.

## Knowledge of diabetes management

A statistically significant difference was found between the three groups in their knowledge of diabetes management, F(2,232) = 5.71, p<0.01. The  $\eta^2$  was found to be 0.05 stating that the influence of duration of disease on knowledge of diabetes management is small. The Tukey's HSD score presented in table 4 indicated a statistically significant difference between group I (M=2.99, SD=.98) and group III (M=3.48, SD=.89) in their knowledge of diabetes management (MD=.49, p<0.01). Whereas, no significant difference was found between group I and group II and between group II and group III.

# **Social support**

There was no significant difference between the three groups on the variable of social support and its respective dimensions. The results of which are furnished in Table3.

# Self-efficacy

The results of one-way ANOVA revealed a statistically significant difference between the three groups in their self-efficacy, F(2,232) = 11.94, p<0.001. The  $\eta^2$  was found to be 0.09 stating that the influence of duration of disease on self-efficacy is large. The Tukey's HSD score presented in Table 4 indicated a statistically significant difference between group I (M=52.96, SD=8.68) and group II (M=57.37, SD=11.15) in their level of self-efficacy (MD=4.41, p<0.05). Group I (M=52.96, SD=8.68) was found to be significantly different from group III (M=60.48, SD=8.91) in their level of selfefficacy (MD=7.52, p<0.001). Whereas, no significant difference was found between group II and group III.

#### Adherence

The results of one-way ANOVA revealed a statistically significant difference between the three groups on the dimensions of adherence namely medicine and diet. No significant difference was observed among the three groups in the overall level of adherence score and on the dimensions of exercise, blood glucose monitoring and doctor's consultation.

#### Adherence to medicine

The results of one-way ANOVA revealed a statistically significant difference between the three groups in their adherence to medicine, F(2,232) = 7.37, p<0.01. The  $\eta^2$  was found to be 0.06 stating that the influence of duration of disease on adherence to medicine is medium. The Tukey's HSD score presented in Table 4 indicated a statistically significant difference between group I (M=26.45, SD=1.59) and group II (M=27.19, SD=1.79) in their level of adherence to medicine (MD=.74, p<0.05). Group I (M=26.45, SD=1.59) was found to be significantly different from group III (M=27.38, SD=1.34) in their level of adherence to medicine (MD=.93, p<0.01). Whereas, no significant difference was found between group II and group III.

## Adherence to diet

The results of one-way ANOVA revealed a statistically significant difference between the three groups in their adherence to diet, F(2,232) = 4.42, p<0.05. The  $\eta^2$  was found to be 0.04 stating that the influence of duration of disease on adherence to diet is small. The Tukey's HSD score presented in Table 4 indicated a statistically significant difference between group I (M=10.83, SD=1.14) and group III (M=11.28, SD=.75) in their level of adherence to diet (MD=.45, p<0.05). Whereas, no significant difference was found between group I and group II and also between group II and group III.

#### **Quality of life**

The results of one-way ANOVA revealed a statistically significant difference between the three groups on only one dimension of quality of life namely social burden. There was no significant difference observed among the three groups in the overall quality of life score and on the dimensions of diabetes control, anxiety and worry, sexual functioning, and energy and mobility.

## Social burden

The results of one-way ANOVA revealed a statistically significant difference between the three groups on the dimension of quality of life namely social burden, F(2,232) = 8.18, p < 0.001. The  $\eta^2$  was found to be 0.07 stating that the influence of duration of disease on social burden dimension is medium. The Tukey's HSD score presented in Table 4 indicated a statistically significant difference between group I (M=15.64, SD=13.23) and group II (M=11.05, SD=7.64) in their level of social burden (MD=4.59, p < 0.01). Group I (M=15.64, SD=13.23) was found to be significantly different from group III (M=9.78, SD=6.29) in their level of social burden (MD=5.86, p<0.001). Whereas, no significant difference was found between group II and group III.

The differences in mean values of the three groups are illustrated through a bar graph. Figure 1 depicts the mean values of the total knowledge of diabetes and only three of its dimensions, on which the three groups differed significantly.

Following which analyses were done to assess the impact of the predictor variables on criterion variables, for which Pearson's correlation (r), multiple linear regression and path analysis were performed.

The impact of knowledge of diabetes, social support, and self-efficacy on adherence and quality of life

Relationship among the measures and their respective dimensions for the entire sample

Pearson's correlation (r) was used to find out the relationship between demographic details (age, gender, education and duration of disease), knowledge of diabetes (dimensions: symptoms, causes, complications, and management), social support (dimensions: appraisal, tangible, belonging and self-esteem), self-efficacy, adherence (dimensions: medicine, diet, exercise, blood glucose monitoring, and doctor's consultation), quality of life (dimensions: diabetes control, anxiety and worry, social burden, sexual functioning, and energy and mobility).

## Relationship between demographic details and the rest of the variables

# (a) Relationship between age and other variables

As seen in the Table 5, the results revealed a significant negative relationship between age and the dimensions of knowledge of diabetes symptoms r= -.21, p<0.01, causes r= -.26, p<0.001, complications r= -.01, p<0.05, and total diabetes knowledge r= -.19, p<0.01. This implies that there is an inverse correlation between age and the dimensions of knowledge of diabetes. In other words, lesser the age of a person higher is their knowledge of diabetes, its symptoms, causes and complications. However, no significant correlation was found between age and the dimension of knowledge of diabetes management.

Variables	D1	D2	D3	D4	D_T	<b>S</b> 1	S2	<b>S</b> 3	S4	S_T	Se
Age	21**	26***	01	.03	19**	05	03	03	04	06	01
Gender	13*	28***	06	.10	18**	01	21**	07	09	12	10
Education	.19**	.45***	.29***	.02	.38***	04	.08	.16*	04	.03	.24***
Duration of disease	.13	.02	.09	.17**	.12	05	07	06	04	08	.26***

Table 5Table showing intercorrelations among demographic variables and the rest of the variables under study

Table 5 (continued)

Variables	A1	A2	A3	A4	A5	A_T	Q1	Q2	Q3	Q4	Q5	Q_T
Age	.22**	.12	13	11	.09	.01	26***	21**	34***	01	.09	19**
Gender	.16*	.21**	21**	01	.07	05	01	.03	11	07	.23***	.01
Education	13*	22**	.20**	.12	24***	.04	.05	09	.19**	04	22**	04
Duration of disease	$.18^{**}$	$.17^{*}$	03	01	.05	.08	04	08	18**	.10	.10	02

*Note.* D1- DKT-I Symptoms, D2- DKT-I Causes, D3- DKT-I Complications, D4- DKT-I Management, D\_T-DKT-I Total; S1- Appraisal Support, S2- Tangible Support, S3- Belongingness Support, S4- Self-esteem Support, S\_T- Social Support Total; Se- Self-efficacy; A1- Adherence to Medicine, A2- Adherence to Diet, A3- Adherence to Exercise, A4- Adherence to Blood Glucose Monitoring, A5- Adherence to Doctor's Consultation, A\_T- Adherence Total; Q1- QOL Diabetes Control, Q2- QOL Anxiety Worry, Q3- QOL Social Burden, Q4- QOL Sexual Functioning, Q5- QOL Energy Mobility, Q\_T- Quality Of Life Total \**p*<0.05, \*\**p*<0.01, \*\*\**p*<0.001

The results revealed no significant relationship between age and social support and its dimensions. Also no significant relationship was found between age and selfefficacy.

A positive significant relationship was found between age and the dimension of adherence to medicine r=.22, p<0.01. This indicates that as one's age increases their adherence to medicine also increases. However, no significant relationship was found between age and overall adherence or between age and other dimensions of adherence namely diet, exercise, blood glucose monitoring and doctor's consultation.

The results revealed a significant negative relationship between age and overall quality of life r = -.19, p < 0.01 and three of its dimensions namely diabetes control r = -.26, p < 0.001, anxiety and worry r = -.21, p < 0.01, social burden r = -.34, p < 0.001. This implies that as age increases the score of quality of life decreases. As mentioned in the method chapter, low score on quality of life measure indicates high quality of life. Therefore it can be said here, that as age increases, and overall quality of life increases, in addition to increase in its specific dimensions of diabetes control, anxiety worry, and social burden. However, there was no significant relationship between age and the dimensions of sexual functioning and energy and mobility.

#### (b) Relationship between gender and other variables

As seen in the Table 5, the results revealed a significant negative relationship between gender and the dimension of diabetes symptoms r = -.13, p < 0.05, dimension of diabetes causes r = -.28, p < 0.001, and total diabetes knowledge r = -.18, p < 0.01. For the analysis, male participants were assigned '0' and female participants were assigned '1'. In this context, it implies that there is an inverse correlation between gender and the dimensions of knowledge of diabetes. In other words, men have higher knowledge of diabetes, its symptoms, and causes than women. However, there was no significant correlation between gender and the dimension of knowledge of diabetes complications and management.

The results revealed a significant negative relationship between gender and one dimension of social support namely tangible support r= -.21, p<0.01. This implies that males have better tangible support than females. However, no significant relationship was found between total social support and other dimensions.

The results revealed no significant relationship between gender and self-efficacy. A positive significant relationship was also found between gender and the dimension of adherence to medicine r=.16, p<0.05, adherence to diet r=.21, p<0.01 and a significant negative relationship was found between gender and adherence to exercise r=-.21, p<0.01. This indicates that males have better adherence to medicine and diet, while females have better adherence to exercise. However, no significant relationship was found between gender and other dimensions of adherence namely blood glucose monitoring and doctor's consultation.

The results revealed a significant positive relationship between gender and of its dimensions namely energy mobility r=.23, p<0.001. This implies that females have higher score on this dimension. As mentioned in the method chapter, high score on quality of life measure indicates low quality of life. Therefore it can be said here, that

females have low quality of life in the area of energy and mobility. However, there was no significant relationship between gender and overall QOL and other dimensions.

#### (c) Relationship between education and other variables

As seen in the Table 5, the results revealed a significant positive relationship between level of education and the dimension of knowledge of diabetes symptoms r= .19, p<0.01, dimension of knowledge of diabetes causes r= .45, p<0.001, dimension of knowledge of diabetes complications r= .29, p<0.001, and total diabetes knowledge r= .38, p<0.001. This implies that there is correlation between education and the dimensions of knowledge of diabetes. In other words, higher the level of education higher is their knowledge of diabetes, its symptoms, causes and complications. However, there was no significant correlation between level of education and the dimension of diabetes management.

The results revealed significant positive relationship between education and social support and one of its dimensions namely belonging r= .16, p<0.05. This implies that as the level of education increases, their level of belonging support also increases. However, there was no significant relationship found between level of education and other dimensions of social support and overall social support.

A positive significant relationship was also found between level of education and self-efficacy r= .24, p<0.001.This implies that as level of education increases, the level of self-efficacy also increases.

The results revealed a significant positive relationship between level of education and the dimensions of adherence namely adherence to exercise r=.20, p<0.01, and a negative relationship was found between level of education and adherence to medicine r = -.13, p < 0.05, adherence to diet r = -.22, p < 0.01, adherence to doctor's consultation r = -.24, p < 0.001. This indicates that as one's level of education increases adherence to exercise also increases and as one's level of education increases their adherence to medicine, diet and doctor's consultation decreases. However, no significant relationship was found between level of education and overall adherence or between level of education and other dimension of adherence namely blood glucose monitoring.

The results revealed a significant positive relationship between level of education and the dimension of social burden of QOL r= .19, p<0.01 and a negative relationship was found between level of education and the dimension of energy and mobility of QOL r= -.22, p<0.01. This implies that as level of education increases the score of social burden of QOL increases and the score of energy mobility decreases. As mentioned in the method chapter, high score on quality of life measure indicates low quality of life, and vice versa. Therefore it can be said here, that as level of education increases, QOL related to social burden decreases and as the level of education increases, QOL related to energy mobility also increases. However, there was no significant relationship between level of education and the dimensions of diabetes control, anxiety worry, sexual functioning and overall QOL.

#### (d) Relationship between duration of disease and other variables

As seen in the Table 5, the results revealed a significant positive relationship between duration of disease and the dimension of knowledge of diabetes management r=.17, p<0.01. This implies that longer the duration of disease higher is their knowledge of diabetes management. However, there was no significant correlation between duration of disease and the dimensions of knowledge of diabetes symptoms, causes and complications.

The results however revealed no significant relationship between duration of disease and social support and its dimensions.

A significant positive relationship was found between duration of disease and self-efficacy r= .26, p<0.001.This implies that as duration of disease increases, the level of self-efficacy also increases.

The results revealed a significant positive relationship between duration of disease and the dimensions of adherence namely adherence to medicine r= .18, p<0.01, and adherence to diet r= .17, p<0.05. This indicates that as one's duration of disease increases adherence to medicine and diet also increases. However, no significant relationship was found between duration of disease and overall adherence or between duration of disease and other dimensions of adherence namely exercise, blood glucose monitoring and doctor's consultation.

The results revealed a significant negative relationship between duration of disease and the dimension of social burden of QOL r= -.18, p<0.01. This implies that as duration of disease increases the score of social burden of QOL decreases. As mentioned in the method chapter, low score on quality of life measure indicates high quality of life. Therefore it can be said here, that as duration of disease increases, QOL related to social burden also increases. However, there was no significant relationship between duration of

disease and the dimensions of diabetes control, anxiety worry, sexual functioning, energy and mobility and overall QOL.

Following which Pearson's correlation was also conducted to understand the relationship between knowledge of diabetes with social support, self-efficacy, adherence and quality of life and their respective dimensions

# Relationship of knowledge of diabetes with social support, self-efficacy, adherence and quality of life and their respective dimensions

#### (a) Relationship between knowledge of diabetes symptoms and other variables

As seen in Table 6, the results revealed no significant relationship between knowledge of diabetes symptoms and social support and its dimensions.

A significant positive relationship was found between knowledge of diabetes symptoms and self-efficacy r=.29, p<0.001. This implies that as knowledge of diabetes symptoms increases, the level of self-efficacy also increases.

The results revealed a significant positive relationship between knowledge of diabetes symptoms and the dimensions of adherence namely adherence to diet r= .14, p<0.05, adherence to exercise r= .19, p<0.01, adherence to blood glucose monitoring r= .13, p<0.05, and over adherence r= .22, p<0.01. This indicates that as one's knowledge of diabetes symptoms increases adherence to diet, exercise, blood glucose monitoring and overall adherence also increases. However, no significant relationship was found between knowledge of diabetes symptoms and adherence to medicine and doctor's consultation.

# Table 6

Table showing intercorrelations between knowledge of diabetes with social support, self-efficacy, adherence and quality of life and their respective dimensions

	<b>S</b> 1	S2	<b>S</b> 3	<b>S</b> 4	S_T	Se	A1	A2	A3	A4	A5	A_T	Q1	Q2	Q3	Q4	Q5	Q_T
D1	.12	03	.01	.01	.06	.29***	.08	.14*	.19**	.13*	03	.22**	.09	.12	.01	.15*	01	.12
D2	.13*	.08	.12	.03	.14*	.34***	06	16*	.22**	.18**	13*	.12	.15*	.01	.19**	.07	04	.09
D3	.13*	.07	.07	03	.12	.27***	02	01	.19**	.07	.03	.15*	.00	09	07	02	09	08
D4	.06	.12	.04	06	.08	.26***	.15*	.10	.09	.11	.07	.17**	.01	.06	03	.04	.05	.05
D_T	.16*	.07	.09	01	.15*	.41***	.02	09	.26***	.17**	05	.22**	.10	.02	.06	.08	05	.07

*Note*. D1- DKT-I Symptoms, D2- DKT-I Causes, D3- DKT-I Complications, D4- DKT-I Management, D\_T-DKT-I Total; S1- Appraisal Support, S2- Tangible Support, S3- Belongingness Support, S4- Self-esteem Support, S\_T- Social Support Total; Se- Self-efficacy; A1- Adherence to Medicine, A2- Adherence to Diet, A3- Adherence to Exercise, A4- Adherence to Blood Glucose Monitoring, A5- Adherence to Doctor's Consultation, A\_T- Adherence Total; Q1- QOL Diabetes Control, Q2- QOL Anxiety Worry, Q3- QOL Social Burden, Q4- QOL Sexual Functioning, Q5- QOL Energy Mobility, Q\_T- Quality Of Life Total \**p*<0.05, \*\**p*<0.01, \*\*\**p*<0.001

The results revealed a significant positive relationship between knowledge of diabetes symptoms and the dimension of sexual functioning of QOL r= .15, p<0.05. This implies that as knowledge of diabetes symptoms increases the score of sexual functioning of QOL increases. As mentioned in the method chapter, high score on quality of life measure indicates low quality of life. Therefore it can be said here, that as knowledge of diabetes symptoms increases, QOL related to sexual functioning decreases. However, there was no significant relationship between knowledge of diabetes symptoms and the dimensions of diabetes control, anxiety worry, social burden, energy and mobility and overall QOL.

#### (b) Relationship between knowledge of diabetes causes and other variables

The results revealed significant positive relationship between knowledge of diabetes causes and overall social support r= .14, p<0.05 and one of its dimensions namely appraisal support r= .13, p<0.05. This implies that as knowledge of diabetes causes increases, social support also increases. However there was no significant difference found between the dimensions of tangible support, belonging support and self-esteem support and knowledge of diabetes causes.

As seen in Table 6, the significant positive relationship was found between knowledge of diabetes causes and self-efficacy r=.34, p<0.001. This implies that as knowledge of diabetes causes increases, the level of self-efficacy also increases.

The results revealed a significant positive relationship between knowledge of diabetes causes and the dimensions of adherence namely adherence to exercise r= .22, p<0.01, adherence to blood glucose monitoring r= .18, p<0.01, and significant negative

relationship was observed between knowledge of diabetes causes and adherence to diet r = -.16, p < 0.05 and doctor's consultation r = -.13, p < 0.05. This indicates that as one's knowledge of diabetes causes increases adherence to exercise, and blood glucose monitoring also increases. And as one's knowledge of diabetes causes increases adherence to diet and doctor's consultation decreases. However, no significant relationship was found between knowledge of diabetes causes and adherence to medicine and overall adherence.

The results revealed a significant positive relationship between knowledge of diabetes causes and the dimension of diabetes control of QOL r= .15, p<0.05, and the dimension of social burden r= .19, p<0.01. This implies that as knowledge of diabetes causes increases the score of diabetes control and social burden of QOL increases. As mentioned in the method chapter, high score on quality of life measure indicates low quality of life. Therefore it can be said here, that as knowledge of diabetes causes increases, QOL related to diabetes control and social burden decreases. However, there was no significant relationship between knowledge of diabetes causes and the dimensions of anxiety worry, sexual functioning, energy and mobility and overall QOL.

# (c) Relationship between knowledge of diabetes complications and other variables

The results revealed significant positive relationship between knowledge of diabetes complications and one of its dimensions of social support namely appraisal support r=.13, p<0.05. This implies that as appraisal support increases, knowledge of diabetes complications increases. However there was no significant difference found

between overall social support and the dimensions of tangible support, belonging support and self-esteem support and knowledge of diabetes complications.

A significant positive relationship was found between knowledge of diabetes complications and self-efficacy r=.27, p<0.001. This implies that as knowledge of diabetes complications increases, the level of self-efficacy also increases.

The results revealed a significant positive relationship between knowledge of diabetes complications and the dimensions of adherence namely adherence to exercise r= .19, p<0.01, and overall adherence r= .56, p<0.05. This indicates that as one's knowledge of diabetes complications increases adherence to exercise, and overall adherence also increases. However, no significant relationship was found between knowledge of diabetes complications and adherence to medicine, diet, blood glucose monitoring and doctor's consultation.

The results revealed no significant relationship between knowledge of diabetes complications and overall QOL and its dimensions.

# (d) Relationship between knowledge of diabetes management and other variables

The results revealed no significant relationship between knowledge of diabetes management and overall social support and its dimensions.

A significant positive relationship was found between knowledge of diabetes management and self-efficacy r= .26, p<0.001.This implies that as knowledge of diabetes management increases, the level of self-efficacy also increases.

The results revealed a significant positive relationship between knowledge of diabetes management and the dimensions of adherence namely adherence to medicine r=.15, p<0.05, and overall adherence r=.17, p<0.01. This indicates that as one's knowledge of diabetes management increases adherence to medicine, and overall adherence also increases. However, no significant relationship was found between knowledge of diabetes management and adherence to diet, exercise, blood glucose monitoring and doctor's consultation.

The results revealed no significant relationship between knowledge of diabetes management and overall QOL and its dimensions.

#### (e) Relationship between overall knowledge of diabetes and other variables

The results revealed significant positive relationship between overall knowledge of diabetes and overall social support r=.15, p<0.05, and one of its dimensions namely appraisal support r=.16, p<0.05. This implies that as overall support and appraisal support increases, overall knowledge of diabetes also increases. However there was no significant difference found between overall knowledge of diabetes and the dimensions of tangible support, belonging support and self-esteem support.

A significant positive relationship was found between overall knowledge of diabetes and self-efficacy r=.41, p<0.001. This implies that as overall knowledge of diabetes increases, the level of self-efficacy also increases.

The results revealed a significant positive relationship between overall knowledge of diabetes and the dimensions of adherence namely adherence to exercise r=.26, p<0.001, adherence to blood glucose monitoring r=.17, p<0.01, and overall adherence

r=.22, p<0.01. This indicates that as one's overall knowledge of diabetes increases adherence to exercise, blood glucose monitoring and overall adherence also increases. However, no significant relationship was found between overall knowledge of diabetes and adherence to medicine, diet, blood and doctor's consultation.

The results revealed no significant relationship between overall knowledge of diabetes and overall QOL and its dimensions.

Relationship of social support with self-efficacy, adherence and quality of life and their respective dimensions

# (a) Relationship between appraisal support and other variables

Table 7 shows the results which revealed no significant relationship between appraisal support and self-efficacy.

The results revealed a significant positive relationship between appraisal support and the dimensions of adherence namely adherence to blood glucose monitoring r= .14, p<0.05. This indicates that as one's appraisal support increases adherence to blood glucose monitoring also increases. However, no significant relationship was found between appraisal support and adherence to medicine, diet, exercise, doctor's consultation and overall adherence.

The results revealed no significant relationship between appraisal support and QOL and its dimensions.

# Table 7

Table showing inter-correlation between social support, self-efficacy, adherence and quality of life and their respective dimensions

Variables	Se	A1	A2	A3	A4	A5	A_T	Q1	Q2	Q3	Q4	Q5	Q_T
S1	.06	02	.12	09	.14*	02	04	.12	.05	.12	.02	.07	.09
S2	.07	.01	04	01	01	05	02	.01	08	.08	.01	01	02
<b>S</b> 3	.08	.07	.02	.07	.01	17*	.07	02	10	.06	.03	05	03
S4	.04	.20**	.23***	.14*	03	.09	.24***	09	17*	.01	.11	09	07
S_T	.08	.04	.11	02	.08	05	.02	.06	05	.12	.04	.02	.03

*Note.* S1- Appraisal Support, S2- Tangible Support, S3- Belongingness Support, S4- Self-esteem Support, S\_T- Social Support Total; Se- Self-efficacy; A1-Adherence to Medicine, A2- Adherence to Diet, A3- Adherence to Exercise, A4- Adherence to Blood Glucose Monitoring, A5- Adherence to Doctor's Consultation, A\_T- Adherence Total; Q1- QOL Diabetes Control, Q2- QOL Anxiety Worry, Q3- QOL Social Burden, Q4- QOL Sexual Functioning, Q5- QOL Energy Mobility, Q\_T- Quality Of Life Total p<0.05, p<0.01, p<0.001

#### (b) Relationship between tangible support and other variables

There was no significant relationship found between tangible support and other variables namely self-efficacy, adherence and QOL and their respective dimensions.

# (c) Relationship between belonging support and other variables

There was no significant relationship found between belonging support and selfefficacy.

The results revealed a significant negative relationship between belonging support and the dimensions of adherence namely adherence to doctor's consultation r= -.17, p<0.05. This indicates that as one's belonging support increases adherence to doctor's consultation also increases. However, no significant relationship was found between belonging support and adherence to medicine, diet, exercise, blood glucose monitoring, and overall adherence.

#### (d) Relationship between self-esteem support and other variables

The results revealed no significant relationship between self-esteem support and self-efficacy.

The results revealed a significant positive relationship between self-esteem support and the dimensions of adherence namely adherence to medicine r=.20, p<0.01, adherence to diet r=.23, p<0.001, adherence to exercise r=.14, p<0.05, and overall adherence r=.24, p<0.001. This indicates that as one's self-esteem support increases adherence to medicine, diet, exercise and overall adherence also increases. However, no

significant relationship was found between self-esteem support and adherence to blood glucose monitoring, and doctor's consultation.

The results revealed significant negative relationship between self-esteem support and one of the dimensions of QOL namely anxiety worry r= -.17, p<0.05. This implies that as self-esteem support increases the score of QOL dimension anxiety worry decreases. As mentioned in the method chapter, low score on the measure of quality of life indicates high quality of life. Therefore it can be said here, that as self-esteem support increases, QOL related to anxiety worry also increases. However, there was no significant relationship between self-esteem support and the dimensions of diabetes control, social burden, sexual functioning, energy and mobility and overall QOL.

## (e) Relationship between overall social support and other variables

There was no significant relationship found between overall support and other variables namely self-efficacy, adherence and QOL and their respective dimensions.

# Relationship between self-efficacy, and adherence, quality of life and their respective dimensions

#### (a) Relationship between self-efficacy, adherence and quality of life

According to table 8 the results revealed a significant positive relationship between self-efficacy and the dimensions of adherence namely adherence to medicine r=.19, p<0.01, adherence to diet r=.17, p<0.05, adherence to exercise r=.59, p<0.001, adherence to blood glucose monitoring r=.15, p<0.05, and overall adherence r=.57, p<0.001. This indicates that as one's self-efficacy increases adherence to medicine, diet, exercise, blood glucose monitoring, and overall adherence also increases. However, no significant relationship was found between self-efficacy and adherence to doctor's consultation.

Table 8

Table showing inter-correlation between self-efficacy, adherence and quality of life and their respective dimensions

Variable	A1	A2	A3	A4	A5	A_T	Q1	Q2	Q3	Q4	Q5	Q_T
SE	.19**	.17*	.59***	.15*	06	.57***	21**	22**	13*	07	26***	24***

Note. SE- Self-efficacy, A1- Adherence to Medicine, A2- Adherence to Diet, A3- Adherence to Exercise, A4- Adherence to Blood Glucose Monitoring, A5- Adherence to Doctor's Consultation, A\_T- Adherence Total; Q1- QOL Diabetes Control, Q2- QOL Anxiety Worry, Q3- QOL Social Burden, Q4- QOL Sexual Functioning, Q5- QOL Energy Mobility, Q\_T- Quality Of Life Total \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

The results revealed significant negative relationship between self-efficacy and dimensions of QOL namely diabetes control r = -.21, p < 0.01, anxiety worry r = -.22, p < 0.01, social burden r = -.13, p < 0.05, energy and mobility r = -.26, p < 0.001, and overall QOL r = -.24, p < 0.001. This implies that as self-efficacy increases the score of QOL dimension diabetes control, anxiety worry, social burden, energy mobility and overall QOL decreases. As mentioned in the method chapter, low score on the measure of quality of life indicates high quality of life. Therefore it can be said here, that as self-efficacy increases, QOL related to diabetes control, anxiety worry, social burden, energy mobility and overall QOL also increases. However, there was no significant relationship between self-efficacy and the dimension of sexual functioning.

Relationship between adherence and quality of life and their respective dimensions

#### (a) Relationship between adherence to medicine and QOL

The results as shown in Table 9 revealed significant negative relationship between adherence to medicine and dimensions of QOL namely diabetes control r= -.41, p<0.001, anxiety worry r= -.22, p<0.01, social burden r= -.32, p<0.001, energy and mobility r= -.18, p<0.01, and overall QOL r= -.29, p<0.001.

#### Table 9

Table showing inter-correlations between adherence and quality of life and their respective dimensions

Variables	Q1	Q2	Q3	Q4	Q5	Q_T
A1	41***	22**	32***	04	18**	29***
A2	10	.02	04	.05	.06	.01
A3	16*	14*	11	02	27***	18**
A4	.18**	01	.08	14*	.08	.02
A5	28***	08	28***	01	17**	19**
A_T	31***	19**	23***	03	28***	27***

*Note.* A1- Adherence to Medicine, A2- Adherence to Diet, A3- Adherence to Exercise, A4- Adherence to Blood Glucose Monitoring, A5- Adherence to Doctor's Consultation, A\_T- Adherence Total; Q1- QOL Diabetes Control, Q2- QOL Anxiety Worry, Q3- QOL Social Burden, Q4- QOL Sexual Functioning, Q5- QOL Energy Mobility, Q\_T- Quality Of Life Total \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

This implies that as adherence to medicine increases the score of QOL dimensions of diabetes control, anxiety worry, social burden, energy mobility and overall QOL decreases. As mentioned in the method chapter, low score on the measure of quality of life indicates high quality of life. Therefore it can be said here, that as adherence to medicine increases, QOL related to diabetes control, anxiety worry, social burden, energy mobility and overall QOL also increases. However, there was no significant relationship between adherence to medicine and the dimension of sexual functioning.

# (b) Relationship between adherence to diet and QOL

There was no significant relationship found between adherence to diet and QOL and its dimensions.

### (c) Relationship between adherence to exercise and QOL

The results revealed significant negative relationship between adherence to exercise and dimensions of QOL namely diabetes control r= -.16, p<0.05, anxiety worry r= -.14, p<0.05, energy and mobility r= -.27, p<0.001, and overall QOL r= -.18, p<0.01. This implies that as adherence to exercise increases the score of QOL dimensions of diabetes control, anxiety worry, energy mobility and overall QOL decreases. As mentioned in the method chapter, low score on the measure of quality of life indicates high quality of life. Therefore it can be said here, that as adherence to exercise increases, QOL related to diabetes control, anxiety worry, energy mobility and overall QOL also increases. However, there was no significant relationship between adherence to exercise and the dimensions of social burden, and sexual functioning.

### (d) Relationship between adherence to blood glucose monitoring and QOL

The results revealed significant positive relationship between adherence to blood glucose monitoring and diabetes control r= .18, p<0.01, and a negative relationship with

sexual functioning r= -.14, p<0.05. This implies that as adherence to blood glucose monitoring increases the score of QOL dimension of diabetes control increases and sexual functioning decreases. As mentioned in the method chapter, low score on the measure of quality of life indicates high quality of life and vice versa. Therefore it can be said here, that as adherence to blood glucose monitoring increases, QOL related to diabetes control decreases and sexual functioning increases. However, there was no significant relationship between adherence to blood glucose monitoring and the dimensions of anxiety worry, social burden, energy mobility and overall QOL.

#### (e) Relationship between adherence to doctor's consultation and QOL

The results revealed significant negative relationship between adherence to doctor's consultation and dimensions of QOL namely diabetes control r= -.28, p<0.001, social burden r= -.28, p<0.001, energy and mobility r= -.17, p<0.01, and overall QOL r= -.19, p<0.01. This implies that as adherence to doctor's consultation increases the score of QOL dimensions of diabetes control, social burden, energy mobility and overall QOL decreases. As mentioned in the method chapter, low score on the measure of quality of life indicates high quality of life. Therefore it can be said here, that as adherence to doctor's consultation increases, QOL related to diabetes control, social burden, energy mobility and overall QOL also increases. However, there was no significant relationship between adherence to doctor's consultation and the dimensions of anxiety worry, and sexual functioning.

#### (f) Relationship between overall adherence and QOL

The results revealed significant negative relationship between overall adherence and dimensions of QOL namely diabetes control r= -.31, p<0.001, anxiety worry r= -.19, p<0.01, social burden r= -.23, p<0.001, energy and mobility r= -.28, p<0.001, and overall QOL r= -.27, p<0.001. This implies that as overall adherence increases the score of QOL dimensions of diabetes control, anxiety worry, social burden, energy mobility and overall QOL decreases. As mentioned in the method chapter, low score on the measure of quality of life indicates high quality of life. Therefore it can be said here, that as overall adherence increases, QOL related to diabetes control, anxiety worry, social burden, energy mobility and overall QOL also increases. However, there was no significant relationship between overall adherence and the dimension of sexual functioning.

After finding that there exists a relationship between the variables under study, multiple linear regressions ware performed. In the first phase, two multiple linear regressions were performed to assess the role of predictor variables namely demographic variables (age, gender, education, and duration of disease), knowledge of diabetes, social support and self-efficacy on adherence and QOL. The results of have been explained below.

#### **Role of predictor variables on adherence**

For the analyses relating to adherence, the variables age, gender, education, duration of disease, diabetes knowledge, social support and self-efficacy were entered as predictors. A significant model as seen in Table 10, comprising age, gender, education, duration of disease, overall diabetes knowledge, social support and self-efficacy was found.

# Table 10

Table showing summary of multiple linear regression for variables predicting adherence (N = 235)

Predictors	В	SEB	β	t
Age	0.01	0.02	0.02	0.39
Gender	-0.23	0.53	-0.02	0.43
Education	-0.33	0.15	-0.13	2.10*
Duration of disease	-0.09	0.05	-0.10	1.67
Diabetes knowledge	0.03	0.05	0.04	0.65
Social support	-0.01	0.01	-0.04	0.73
Self-efficacy	0.27	0.02	0.61	9.97***
$R^2$	0.34			
С	38.06			
F	16.88***			

*Note.* Criterion= Adherence, *B*=Unstandardized beta coefficient, *SEB* = Standardized Error of Beta,  $\beta$  = Standardized beta coefficient, *t*- t test,  $R^2$  = Variance, *C*= Constant, *F*=*F*- statistic \*p<0.05, \*\*p<0.01, \*\*\*p<0.001 The model explained 34% of variance in adherence,  $R^2$ = .34, F(7, 227) = 16.88, p < .001. It is of significance to note here that personal factors and social support together contributed up to 34% to adherence in type 2 diabetes patients. The significant independent predictors contributing to adherence were education and self-efficacy. Education was significant negative and independent predictor ( $\beta$ = -0.13, p< .05) whereas self-efficacy ( $\beta$ = 0.61, p< .001) was the sole significant positive and independent predictor of adherence.

Table 11

Table showing summary of multiple linear regression for variables predicting quality of life (N = 235)

Predictors	В	SEB	β	t
Age	-0.93	0.29	-0.22	3.21***
Gender	0.34	6.24	0.00	0.05
Education	-2.37	1.86	-0.09	1.27
Duration of disease	0.90	0.62	0.10	1.44
Diabetes knowledge	1.56	0.66	0.17	2.36*
Social support	0.10	0.22	0.02	0.47
Self-efficacy	-0.97	0.38	-0.21	2.52*
Adherence	-1.92	0.77	-0.19	-2.50*
$R^2$	0.16			

For the analyses relating to quality of life, the variables age, gender, education, duration of disease, diabetes knowledge, social support, self-efficacy and adherence were entered as predictors. A significant model (Table 11) comprising age, gender, education, duration of disease, diabetes knowledge, social support, self-efficacy and adherence was found. The model explained 16% of variance in adherence,  $R^2 = .16$ , F(8, 226) = 5.31, p < .16.001. The significant independent predictors contributing to quality of life were age, diabetes knowledge, self-efficacy and adherence. Among these, the significant negative and independent predictors were age ( $\beta$ = -0.22, p< .01), self-efficacy ( $\beta$ = -0.21, p< .05) and adherence ( $\beta$ = -0.19, p< .05). As mentioned in the method chapter, a low score on quality of life indicates high quality of life, implying that as age, self-efficacy and adherence increases, it has a negative impact of quality of life score. However, this low score on quality of life indicates a high quality of life. The influence of age and selfefficacy was higher than that of adherence on quality of life. Diabetes knowledge  $(\beta = 0.17, p < .05)$  was the sole significant positive and independent predictor of quality of life. This indicates that as diabetes knowledge increased it had a positive impact on quality of life score, implying a low quality of life. Hence age, self-efficacy, adherence and having knowledge about various aspects of diabetes predicted quality of life in type 2 diabetes patients.

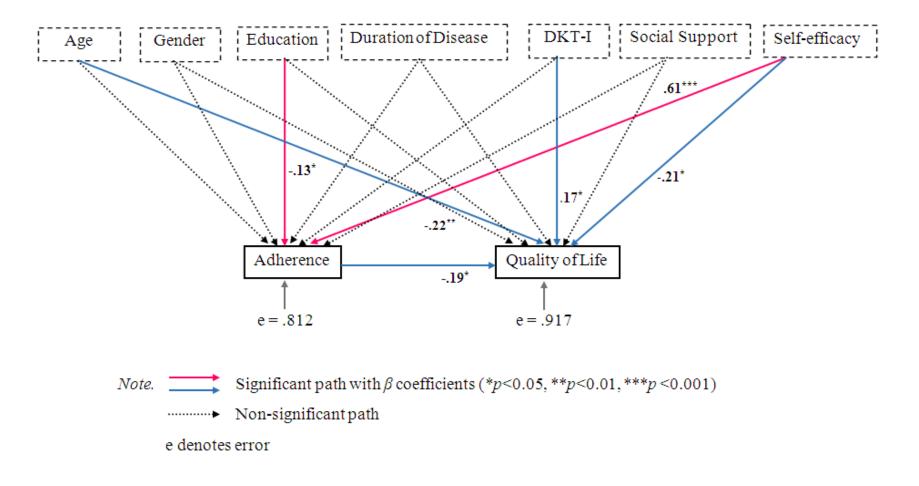
*Note*. Criterion= Quality of life, *B*=Unstandardized beta coefficient, *SEB* = Standardized error of beta,  $\beta$  = Standardized beta coefficient, *t*- t value,  $R^2$  = Variance, *C*= Constant, *F*= *F*- statistic \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

After conducting the two multiple linear regressions, the specific variables which were predicting the criterion variables of adherence and quality of life were identified. Following which a pathway has been depicted to illustrate the pathway of influence of the identified predictor variables on the criterion variables.

The pathway of influence of the predictor variables namely demographic variables of age, gender, education, duration of disease, diabetes knowledge, social support and self-efficacy on adherence and QOL has been illustrated in Figure 3.



Figure illustrating the pathway between psychosocial factors, adherence, and quality of life



The figure shows that among all the predictor variables only education and selfefficacy have direct influence on adherence. Among these two variables self-efficacy ( $\beta$ = 0.61, p< .001) emerged as the largest contributor to adherence behavior while level of education ( $\beta$ = -0.13, p< .05) was found to be a negative contributor to adherence. This indicated that self-efficacy has a major influence on adherence behavior and higher level of education tends to decrease adherence.

Figure 3 also depicts the pathway of the variables influencing QOL. It is seen that age ( $\beta$ = -0.22, p< .01) is the largest negative contributor followed by self-efficacy ( $\beta$ = -0.21, p< .05) and adherence ( $\beta$ = -0.19, p< .05), negatively contributing to QOL. Knowledge of diabetes ( $\beta$ = 0.17, p< .05) was found to have a positive influence on QOL. With the background of the scoring pattern of the instrument used to measure QOL, where in a low score indicates high QOL, it can be said here that self-efficacy is a major predictor of QOL, followed by adherence and age. However it was observed that as knowledge increased, it tended to have a negative influence on QOL, by decreased the QOL.

In the second phase, in order to assess the impact of predictor variables on criterion variables, another set of multiple regressions were performed taking into account those variables which were found to be significant predictors in the first phase. For the analyses relating to adherence, the variables education and self-efficacy were entered as predictors.

# Table 12

Table showing summary of multiple linear regression for education and self-efficacy predicting adherence (N = 235)

Predictors	В	SEB	β	t
Education	-0.25	0.13	-0.10	1.83
Self-efficacy	0.26	0.02	0.59	10.71***
$R^2$	0.33			
С	37.75			
F	57.62***			

*Note.* Criterion= Adherence, *B*=Unstandardized beta coefficient, *SEB* = Standardized error of beta,  $\beta$  = Standardized beta coefficient, *t*- t value,  $R^2$  = Variance, *C*= Constant, *F*= *F*- statistic \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

A significant model (Table 12) comprising education and self-efficacy was found. The model explained 33% of variance in adherence,  $R^2$ = .33, F(2, 232) = 57.62, p < .001. The only significant positive and independent predictor contributing to adherence was self-efficacy ( $\beta$ = 0.59, p < .001). Hence self-efficacy predicted adherence in type 2 diabetes patients.

For the analyses relating to quality of life, the variables age, diabetes knowledge, self-efficacy and adherence were entered as predictors. A model (Table 13) comprising diabetes knowledge, self-efficacy and adherence were found to be significant.

# Table 13

Table showing summary of multiple linear regression for age, diabetes knowledge, selfefficacy and adherence predicting quality of life (N = 235)

Predictors	В	SEB	β	t
Age	-0.70	0.26	-0.16	2.64***
Diabetes knowledge	1.43	0.62	0.16	2.29*
Self-efficacy	-0.92	0.36	-0.20	2.50*
Adherence	-1.91	0.76	-0.19	2.52*
$R^2$	0.14			
С	243.99			
F	9.43***			

*Note.* Criterion= Quality of life, *B*=Unstandardized beta coefficient, *SEB* = Standardized error of beta,  $\beta$  = Standardized beta coefficient, *t*- t value,  $R^2$  = Variance, *C*= Constant, *F*= *F*- statistic \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

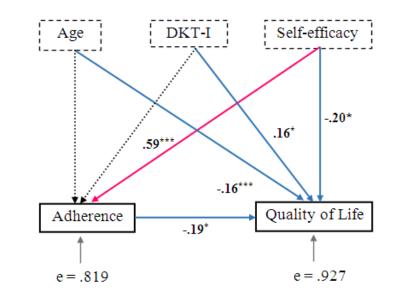
The model explained 14% of variance in QOL,  $R^2$ = .14, F (4, 230) = 9.43, p< .001. The significant independent predictors contributing to quality of life were diabetes knowledge, self-efficacy and adherence. Among these, the significant negative and independent predictors were age ( $\beta$ = -0.16, p< .001), self-efficacy ( $\beta$ = -0.20, p< .05), and adherence ( $\beta$ = -0.19, p< .05). As mentioned in the method chapter, a low score on quality

of life indicates high quality of life, implying that as age, self-efficacy and adherence increases, it has a negative impact of quality of life score. However, this low score on quality of life indicates a high quality of life. Diabetes knowledge ( $\beta$ = 0.16, p< .05) was the sole significant positive and independent predictor of quality of life. This indicates that as diabetes knowledge increased it had a positive impact on quality of life score, implying a low quality of life. Hence self-efficacy, adherence and having knowledge about various aspects of diabetes predicted quality of life in type 2 diabetes patients.

After performing the second phase of multiple linear regressions, another pathway was depicted to illustrate the influence of the identified predictor variables on the criterion variables. The pathway of influence of the major predictor variables namely diabetes knowledge, and self-efficacy on adherence and QOL has been illustrated in the following figure.

# Figure 4

Figure illustrating the pathway between age, knowledge, self-efficacy, adherence, and quality of life



Note. Significant path with  $\beta$  coefficients (\*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001) Non-significant path e denotes error

The figure shows that among major predictor variables only self-efficacy positively predicted adherence behavior ( $\beta$ = 0.59, p< .001). QOL was negatively influenced by self-efficacy ( $\beta$ = -0.20, p< .05), adherence ( $\beta$ = -0.19, p< .05) and positively influenced by knowledge of diabetes ( $\beta$ = 0.16, p< .05). This indicated that self-efficacy has a major influence on adherence behavior. Self-efficacy is a major predictor of QOL, followed by adherence, however as knowledge increased; it tended to have a negative influence on QOL, by decreased the QOL.

The second phase of multiple regression analyses included only those predictors that were found to be significant in the first phase of regression analysis. This was done to arrive at a reduced path model that would be as good a fit to the data as the full path model which was arrived after the first phase of the regression analysis. To test whether

the reduced path model was as good as the full path model, the models were tested and compared. To test the fit of the full model and the reduced model, the formula which was used was 1- $\Pi$  (error<sup>2</sup>), where  $\Pi$  implies the product. The value of the fit of the full model was found to be 0.45 and that of the reduced model was found to be 0.42. To calculate the relative fit of the reduced model to full model, the following formula was used—Q=(1- fit of full model)/ (1-fit of reduced model), which was found to be 0.95. To find out whether this value was significant, the following formula was used— $W=-(N-d) \times \log_e Q$ , where W is interpreted as chi-square with df = d (number of paths dropped in the reduced model) and N is the sample size. The value of W, upon analysis was found to be 11.30, which was lesser than the critical value of 16.92 found in the  $X^2$  distribution for df= 9, p< .05. This indicates that there exists no significant difference in the fit of the full and the reduced model. In other words, the reduced path model with fewer paths than the full model did not differ significantly from the full model. The analysis shows that the reduced path model is sufficient to predict the criterion variables under study rather than having to measure all the variables that were dropped from the full path model. In other words, in order to predict the criterion variables of adherence and quality of life, knowing one's chronological age and measuring one's self-efficacy, and knowledge of diabetes is enough to make the prediction instead of measuring all the variables that were included in the full path model.

#### **Investigator's Observation**

To begin with, the experience of the researcher throughout the research work for this study was marked with curiosity, excitement and productive interaction with both the doctors and the patients. In the initial stages of the research when few of the instruments were being developed specifically for this study, few of the hospitals and clinics were visited. More often than not, the response of the hospital authorities and that of the doctors was positive. They willingly gave their inputs and feedback about the research instruments, and were encouraging. They reported that there was a real dearth of such research work and awareness about psychological issues, at the grass root level, and expressed their happiness of the initiative taken by the researcher. The support staff of the hospitals also showed their interest and support all throughout the research work and data collection, and willingly shared their space to accommodate the researcher and patients while filling up the questionnaires. When the researcher approached the patients, their initial reaction was that of hesitation and intrigue, however, as the researcher spoke to them and built a healthy rapport, very soon, they were comfortable. As they were briefed about the general outline of the research, they expressed their interest and curiosity to answer the questionnaires and were eager to know about the various elements that influence their behavior and the management of diabetes. As they were filling out the questionnaires, especially on social support, hesitation was noticed among few of the respondents who lacked support from their dear ones. They were reluctant to give honest responses. Hesitation on the part of the respondents was also noticed during answering questionnaire on quality of life, where items related to their sexual functioning were present. It was noticed that most of the patients, both young and old, faced serious issues in this area, and were very hesitant to give honest responses, and therefore most of them did not answer them honestly and few brushed it away. Very few numbers of patients, openly spoke about it. This is one area where patients need psychological support and help from health psychologists and clinicians to deal with it in a healthy manner. While answering the other questionnaires, respondents were honest, and in the process, they reflected on their behavior, introspecting whether they actually performed and how to improve their adherence behaviors. Patients seemed to gain an insight into the importance of the elements mentioned in the questionnaires and were able to identify their strengths and shortcomings in the treatment management.

Towards the end of the research work, the researcher came to an understanding that there is a real dearth of holistic treatment approach in helping patients with diabetes. Patients lack the understanding of the importance of psychological elements that play a role in their treatment and overall well-being. Patients view their illness with a very limited medical perspective, assuming that just by consuming timely medication is going to be enough and perform exercise or follow diet regimen thinking of it to be a burden. The most striking observation of the researcher was that, most of the patients seem to be burdened by the illness and find it difficult to manage and become anxious, even if their glycemic levels are well in control. Whereas few of the patients, managed it well, and made an effort to bring down their high glycemic levels with ease and calmness. The more they magnified their illness, the more difficult patients found it to manage their illness and greater the burden in their personal lives.

On a much personal level, the researcher enjoyed interacting with the patients, getting to know different kinds of people, and get an insight into how they manage their condition. Reflecting on my interactions with the patients also taught me life lessons that no matter what the situation, it is all in the way we perceive it and respond to it that matters the most. The patients also gave their positive feedback on how they benefitted through the interaction, which was an encouragement for the researcher.

Chapter V

# Discussion

The primary aim of the study was to find out the difference in the level of social support, knowledge, self-efficacy, adherence, and quality of life among three groups of Type II diabetes patients categorized on the basis of duration of illness. Secondly, it was aimed to find out the relationship between social support, knowledge, self-efficacy, adherence, and quality of life of Type II diabetes patients. Thirdly, it was aimed to assess the role of social support, knowledge, and self-efficacy in adherence and quality of life of Type II diabetes patients.

Based on the objectives, the first hypothesis stated that there would be a difference in the level of social support, knowledge, self-efficacy, adherence, and quality of life among three groups of Type II diabetes patients categorized on the basis of duration of illness. The hypothesis was accepted as the results have shown that there exists a difference in the level of above mentioned variables, as the duration of the illness increased. As reflected in the results, there existed a difference in the level of knowledge of diabetes and its dimensions, self-efficacy, dimensions of adherence and one dimension of quality of life among the three groups of diabetic patients belonging to the different illness duration. However, there was no difference in the level of social support and its dimensions among the three groups.

The results showed that the three groups of diabetes patients categorized on the basis of duration of illness differed significantly on overall knowledge of diabetes, where duration of illness had a medium effect on the knowledge that patients possess about diabetes. This indicates that a change in duration of illness is likely to bring about a change in the level of knowledge about the illness among these patients. Further analysis, showed a clearer picture that patients with below one year duration of illness (group I) had lower knowledge concerning diabetes than those who were above one year and five years of duration of illness (group II and III). This indicates that those with longer duration of illness have better knowledge about the condition.

On the dimension of knowledge of diabetes symptoms, the groups were found to differ significantly, and the influence of duration of illness on knowledge of diabetes symptoms was found to be medium. Results showed that as duration of illness increased to more than one year and five years (group II and III) patients had better knowledge of diabetes symptoms than those below one year duration period (group I). Group II had the highest level of knowledge of diabetes symptoms. On the dimension of knowledge of diabetes causes, statistically significant difference was not found between the three groups.

On the dimension of knowledge of diabetes complications the three groups differed significantly in their level of knowledge, with duration of illness having a small effect on knowledge of diabetes complications. It was found that the patients above one year to five years of duration of illness (group II) had better knowledge of diabetes complications than those below one year of duration (group I). However, no difference was found in the level of knowledge among those patients belonging to group I and group III and between group II and group III.

On the dimension of knowledge of diabetes management the three groups differed significantly in their level of knowledge, with duration of illness having a small effect on knowledge of diabetes management. It was found that the patients above five years to 20 years of duration of illness (group III) had better knowledge of diabetes management than those below one year of duration (group I). However, no difference was found in the level of knowledge of management among those patients belonging to group I and group II and group III.

This change in the level of knowledge may be attributed to the nature of the illness and its management pattern. Diabetes, being a chronic condition, requires constant monitoring, be it in terms of consuming timely medication, watching one's diet, or subtle changes in their energy levels. Patients suffering from this condition tend to become

astutely aware of physical condition while being cognitively preoccupied with their future, as to the possible complications and ways to manage the condition better. Essentially, diabetes becomes a part of one's life, inclining the patient seek more information about it. With the daily experience of managing the illness, patients tend to gather useful information from concerned family members, friends suffering from the same condition, doctors or health professionals during the consultations, and from the available sources such as internet or related books. Therefore, as results indicate, as the duration of illness increased, patients had better overall knowledge about the condition. Recent studies have shown that persons who have family history of diabetes tend to have better knowledge (Azinge, 2013).

Apart from gaining knowledge from various other sources, persons with diabetes, learn or know about the condition from their personal experience. As the duration keeps increasing, they become more attuned to their own bodies, being aware of the symptoms and become able to identify new symptoms. New symptoms surface with variations in the glycemic levels and the changing severity of the illness, bringing to their awareness the changes in their physiology. The groups were found to have same level of knowledge on the dimension knowledge of diabetes causes, this could be attributed to the information given by the physician, health professionals and family and friends as to the most common causes of diabetes. Interestingly, the results showed that the patients in group II had greatly knowledge of complications than group I or group III. Generally, physicians alert the patients as duration of their illness increases, to be aware and cautious of possible complications that may arise. In addition, leaflets containing diabetes related information is occasionally given to the patients in the clinics and hospitals. These contain information about the possible complications, and precautions. The findings showed that patients belonging to group III had the highest mean on the dimension of knowledge of management, when compared to group II and group I. Apart from the information obtained by from the health care team, family and friends, the personal experience of managing the condition for a long time, gives them the insight about ways of managing the condition better. They become aware of the pattern of personal care that works best for them. Therefore the greater the duration, the greater is the patients' knowledge about its symptoms, complications and management, from information obtained from outside sources and their own personal experience. Studies have shown that knowledge about an illness or a disease is affected by the person's age, gender, and also duration of disease (Abebaw et al., 2007). A study conducted in China to determine the level of knowledge of chronically ill patients about various chronic diseases also found that those who had family history and greater duration of disease had better knowledge. Patients who went for regular check-ups and received instructions from their physicians also had better knowledge (Tian et al., 2011).

However, there was no significant difference on the variable of social support and its dimensions among the groups. This finding may be cultural specific in nature. India is a country where family ties and cohesiveness among relatives and the community are upheld and considered to be important. More often than not, adults even though they are independent tend to reside in their parents' home, and vice versa. When faced with any crisis, the family members and relatives readily offer help and support. Especially in this context, when a member of the family suffers from diabetes, the other members offer care and support, in terms of reminding them to take medication, preparing appropriate meals, accompanying them to visit the doctor or on walks, helping them in testing glucose level at home, and offer necessary morale and support. They receive help and company to do things together like going on vacations or when there is an emergency. Therefore, it can be said from the findings of the study that independent of the duration of illness, diabetes patients in this study received fairly equal amount of support and care from their family and friends. A study conducted on Type I and Type II diabetes patients to assess the relationship between perceived social support and diabetes control found that disease duration did not have any statistical relation with the level of social support among these patients (Tol et al., 2011).

The three groups differed significantly in their level of self-efficacy, with duration of illness having a large effect on self-efficacy of the patients. Results showed that patients with below one year of duration of illness (group I) had significantly lower selfefficacy than those compared to more than one year (group II) and those above five years of duration of illness (group III). Though group II did not significantly differ from group III, group had a higher mean value. This indicates that duration of illness plays a role in increasing one's self-efficacy. Two aspects play a major role in diabetes management, medication regimen as advised by the physician and the second aspect is regulating one's lifestyle to achieve optimal glycemic control, which essentially rests in the hands of the patient. Patients are required not only adhere to medication regimen but also make the required lifestyle changes for which self-efficacy is found to play an important role. Once diagnosed, patients try to change and regulate their lifestyle changes in terms of their diet, exercise, and monitoring their glucose levels. As indicated by the results, initially, patients may lack the self-efficacy required to implement those changes. However, the more they try to organize and execute specific behaviors, and accomplish small, the more likely it is that they will put greater effort to engage in those healthy lifestyle behaviors. Practicing such changes overtime, boosts their confidence and motivates them to sustain these changes despite few setbacks. Achieving their management regimen goals acts as a feedback loop increasing their self-efficacy over a period of time. These findings were corroborated with previous studies. In a study conducted on older patients with longer duration of disease, found that patients reported higher level of satisfaction with diabetesrelated aspects and higher self-efficacy in coping when compared to the lesser age group and duration of illness (Trief, Wade, Pine, & Weinstock, 2003). In another study, selfefficacy concerning self-care behaviors were found to be positively correlated with duration of disease, in addition, a significant level of variance (39.1%) in self-care behavior was attributed to efficacy expectations, outcome expectancies and duration of disease (Wu et al., 2007).

Results also showed that the three groups differed significantly in their adherence to medicine and diet, while they did not differ in their overall adherence levels and in adherence to exercise, blood glucose monitoring and doctor's consultation. A significant difference was found between the three groups in their adherence to medicine, where duration of illness showed a medium effect size on adherence to medicine. The results indicated that patients below one year of duration (group I) had significantly lower level of adherence to medicine than those whose duration was above one year (group II) and five years (group III). However, group II and group III did not differ significantly in their adherence to medicine. A significant difference was found among the three groups on the dimension of adherence to diet, where duration of illness was found to have small effect size on adherence to diet. There was a significantly low adherence to diet in patients whose duration was below one year (group I) when compared with those whose duration was above five years to 20 years (group III). Whereas there was no significant difference between patients in group I and group II and group II and group III in their adherence to diet.

Adherence to treatment and lifestyle regimen is purely a conscious choice and effort of the patient, and their willingness to abide by the recommendations of the physician to which they may or may not comply. Few patients may partial adhere, or intentionally do not adhere to the recommendations. As the results show newly diagnosed patients who are within one year of duration of illness have significantly lesser adherence to medicine and diet when compared to the other two groups of patients. This may be attributed to partial adherence by the patients due to various reasons such as complexity of the treatment (dosage and administration of medicine), side effects of the medicine, more importantly the stress of the diagnosis itself or simply forgetting to take medicine. Few patients may try to take charge of their own treatment and modify the medication regimen or completely ignore parts of it fearing side effects, or due to denial which marks the first year of diagnosis. Similar pattern had been noticed in a study conducted by Gracia-Perez and colleagues (2013), they found that reasons for non-adherence may include age, duration of disease, information about the disease, their perceptions, complexity of doses, psychological and financial factors. In addition, the initial year of diagnosis is especially difficult for the patients as they are still coping with being

diagnosed with a life-long illness, making adjustments in the family and their occupation. Likewise, initially patients may not be readily willing to bring changes to their diet pattern. However, as the treatment progresses, patients do notice the benefits of their adherence in terms of reduction of symptoms, improved glycemic control, and improved energy levels their adherence increases. A study conducted on Ethiopian diabetes patients, to determine factors contributing to adherence towards anti-diabetic medication found that the knowledge of diabetes and duration of disease along with other factors were positively associated with adherence (Abebaw, Messele, Hailu, & Zewdu, 2016). The knowledge of the illness also plays a role in helping them understand the risk of non-adherence and possibility of developing serious complications that could be life-threatening. As the patients weigh the benefits of adherence and risk of non-adherence, they are able to work towards implementing changes in their lifestyle in terms of diet, exercise, medicine and monitoring their glucose levels.

The results showed statistically significant difference between the three groups on only one dimension of quality of life namely social burden. It was found that duration of illness had medium effect size on social burden dimension. Patients whose duration of illness was below one year (group I) were found have low quality of life on dimension of social burden, when compared to those above one year (group II) and five years of duration of illness (group III). There was no significant difference between patients belonging to group II and group III on the dimension of social burden. No significant difference was found among the three groups in their overall quality of life score and on the dimensions of diabetes control, anxiety and worry, sexual functioning, and energy and mobility.

For any given individual, being in good health is an essential and important factor that contributes to their quality of life. In addition to this, individuals seek to be psychologically secure and try to avoid constant worry or anxiety which affects their quality of life negatively. However, when diagnosed with a chronic illness, the initial appraisal of the illness and the patient's coping with the situation has considerable impact on one's quality of life. Once diagnosed, the symptoms, and the treatment impact how a person evaluates their health related quality of life. The findings here also indicate that newly diagnosed patients have low quality of life when compared to patients above one year or five years of diagnosis. Diabetes impacts the optimal level of physical, psychological, emotional and social functioning. Patients experience fatigue, preoccupation with the diagnosis and its long-term consequences affects their concentration, strain in their personal relationships or their role as a spouse and parent. It also affects their overall well-being and life satisfaction. Incorporating lifestyle changes like initiating exercise regime, making changes in diet, monitoring their glucose levels becomes an added burden in initial year. Higher order activities such as engaging in productive leisure activities may also get affected. If the individual is in the peak of their professional life or just beginning their marital life, the blow of being diagnosed with diabetes is even greater. It can be said that coping during initial year is difficult and affects one's quality of life tremendously. A study conducted on individuals between the age range of 15-34 years and belonging to different duration of disease (1, 8, 15, and 24 years) found that newly diagnosed patients had more issues related to their health-related quality of life (Sparring et al., 2013). However, as the duration of illness increases, patients slowly get accustomed to the treatment and lifestyle regimen. Their knowledge

about the illness and self-efficacy at adhering to the doctor's recommendations improves their glycemic control and daily functioning. This in the long run improves their quality of life. Studies also have shown that with increased duration of diabetes, though there was a decline in patients' physical functioning and general health, there was an increase in quality of life related to mental health. Patients reported that they had fewer days when they felt depressed or anxious. It was also reported that though patients had physical limitations, their daily functioning and social functioning was satisfying and much better (Sepulveda et al., 2015; Trief, Wade, Pine, & Weinstock, 2003).

Based on the second objective, the second hypothesis stated that there would be a relationship between social support, knowledge, self-efficacy, adherence, and quality of life, for which Pearson's product moment correlation (r) was calculated. The second hypothesis was also accepted as the results showed that there exists a relationship among the variables. The demographic variables of age, gender, education and duration of illness were also included in the analysis. It was found that as age increased, adherence and quality of life in different dimensions also increased. Age of the patient was found to have no interrelation with social support and self-efficacy. As it was discussed, as age progresses, the efficiency at understanding and executing adherence to self-care behaviors and management of the condition also improves. Gender was found to be correlated to variables, where males were found have greater knowledge about diabetes, higher tangible support, and better adherence to medication and diet and good energy and mobility where as the opposite happened in case of females. However, adherence to exercise of female patients was better and the opposite was true for the male patients. Given the Indian context and culture, males tend to socialize with a wider group of

friends and acquaintances than females, therefore, they had better material support, and gathered more knowledge about diabetes. Males tend to have the support of their spouses by reminding them to take medication, and cooking diabetes appropriate diet. By this they were able to stick to the medication and diet regimen, maintain agility, energy and fitness. The demographic variable of level of education was found to be correlated with the other variables. With an increase in level of education, there seemed to be an increase in knowledge of diabetes, self-efficacy, belongingness support, adherence to exercise and diet, and quality of life concerning energy and mobility. With greater education level, the capacity to know the importance of exercise and diet in diabetes management becomes much clearer to the patients to adhere, helps in their energy and mobility and decreases their social burden. However, with an increase in educational level, there was a decrease in adherence to medicine, diet, and doctor's consultation. This may be referred to the continuum of adherence and non-adherence, where partial adherence is present, as patients tend to modify and adapt the treatment regimen to suit their own belief system and convenience. The demographic variable of duration of illness was found to have correlation with the other variables under study except for social support. It was found that with an increase in duration of illness, patients had better knowledge of diabetes management, self-efficacy, adherence to medication, and diet. However, duration of illness did not have correlation with social support and other dimensions of knowledge of diabetes, adherence and quality of life. Many studies have also reported a correlation between demographic variables such as age, gender, education, and duration of illness and knowledge, social support, self-efficacy (Wu et al., 2007) and adherence (Awodele & Osuolale, 2015), quality of life (Kalda, Ratsep, & Lember, 2008).

Likewise, knowledge of diabetes and its four dimensions were found to be positively correlated with appraisal support. Those who had high appraisal support, seemed to have better knowledge about the illness. Findings indicate that an increase in knowledge about diabetes would lead to an increase in patient's self-efficacy, adherence to medicine, diet, exercise, blood glucose monitoring and overall adherence. However no interrelation was found between knowledge and the dimension of doctor's consultation. Knowledge aspect seemed to have no relationship with the overall quality of life, except for three dimensions, namely social burden, where an increase in knowledge would reduce the perception of being a social burden to others. In addition, an increase in knowledge of diabetes symptoms seemed to decrease patients sexual functioning, and knowledge of causes to reduce quality of life related to diabetes control. On the whole it can be said that knowledge of the illness has a positive correlation with self-efficacy and adherence to treatment and so much with the aspect of quality of life.

The variable of social support was found to be correlated only with adherence and not with quality of life. Appraisal support was correlated with blood glucose monitoring indicating that receiving information about the benefits of monitoring one's glycemic level would help them initiate this behavior and maintain it in the long run. An increase in belongingness support seemed to increase adherence to keeping doctor's consultation schedule. This indicates that the more they knew they belonged to someone; they would take responsibility of taking care of their own health. However, self-esteem seemed to have strong relationship with adherence to medicine, diet, exercise, and overall adherence. This indicates those patients who felt respected, loved and cared for and those who essentially perceived these aspects in their interpersonal relationships, made effort to adhere to most aspects of treatment regimen. A study showed that having strong social ties and support, helped in an increase of adherence to treatment in the long run (Kadirvelu, Sadasivan, & Ng, 2012).

Self-efficacy was found to be positively correlated with all the dimensions of adherence except for the dimension of doctor's consultation. This indicates that as one's level of self-efficacy increases they are able to execute health promoting behaviors in an efficient manner by adhering to medication, following proper diet pattern, maintaining their exercise regimen, and checking their blood glucose levels regularly. As mentioned earlier, as a person initiates and executes a behavior, reaching small goals acts as feedback loop to help them continue the same behavior. While having social support did not associate with one's quality of life, self-efficacy was found to have a positive relationship with quality of life. An increase in self-efficacy levels seemed to be related to improved diabetes control among the patients, decrease their anxiety and worry, and feelings of being a social burden, and also improve their energy, vitality, and mobility. On the whole, self-efficacy was seen to be correlated with overall quality of life. However, the only dimension that was not related to self-efficacy was sexual functioning, as the dysfunction may be essentially biologically oriented. Other studies have also shown similar results, where self-efficacy was found to have significant positive correlation with quality of life (Tol et al., 2015).

Finally, adherence was found to have a significant positive correlation with dimensions of quality of life. Adherence to medicine, exercise, and keeping doctor's consultation was found to have a positive relationship with diabetes control, reduce patient's anxiety and worry, decrease their social burden, and increase their energy and mobility. The dimension of adherence to blood glucose monitoring seemed to have a negative relationship with the quality of life related to diabetes control and a positive one with sexual functioning. However, adherence to diet did not have a relationship with any of the dimensions of quality of life. Adherence to treatment and lifestyle changes is bound to have a positive impact on glycemic level of the patient. And an improvement in glucose levels, leads to optimal functioning improving one's quality of life. Previous research has also shown a similar relationship between adherence and quality of life (Gusmai, Novato, & Nogueira, 2015).

After establishing that there exists a relationship among the variables, the analyses were done to test the third hypothesis which stated that social support, knowledge, and self-efficacy would play a role in adherence and quality of life of Type II diabetes patients. This hypothesis was accepted as the findings show that the predictor variables of knowledge and self-efficacy play a role in adherence and quality of life of Type II diabetes patients. As mentioned in the previous chapter, along with the above mentioned predictor variables, the demographic variables of age, gender, education and duration of illness were also included. The analysis for this objective was done in two phases. In the first phase of analysis, among all the predictor variables which included the demographic variables, only level of education and self-efficacy were found to be significant predictors of adherence. Likewise, the significant predictors of quality of life were found to be age, knowledge of diabetes, self-efficacy and adherence. In the second phase of analysis, only self-efficacy was found to have a significant variance or predictive value on adherence, while age, knowledge of diabetes, self-efficacy and adherence were found to be significant predictors of quality of life among Type II diabetes patients. This analysis

ascertains that the pathway leading to adherence is through self-efficacy, while the pathway leading to quality of life is through age, knowledge of diabetes, self-efficacy and adherence.

Therefore it can be said that though level of education plays a role in adherence, self-efficacy is the strongest contributor to adherence. Self-efficacy is one of the most powerful predictors to ascertain whether an individual succeeds in developing and sustain a behavioral change. According O'Leary (1985) self-efficacy is a stronger predictor of adherence than that of internal locus of control and induced fear to bring about behavioral change. Persons with high perceived self-efficacy possess a greater ability in initiating and sustaining their adherence despite facing sporadic setbacks or failures. Those who have high self-efficacy are physiologically and psychologically stronger and calmer. When faced with a challenge or a stressor, these individuals have a calmer response to the situation. They possess the belief that performing the necessary future action may bring a solution to the situation they are facing. This ability to act in order to solve the problem reduces their anxiety associated with the stressor and impacts their emotion and cognition to set a higher goal. Given in the context on diabetes, individuals who cope well with the diagnosis and are able to accept the situation are inclined to initiate actions to improve their health. As they initiate, the benefits of these health behaviors reinforces or acts as a feedback loop to sustain such behaviors (Rimal, 2000). Diabetes being a chronic illness, the patient needs to sustain these health promoting behaviors for a long period of time, in the face of obstacles and failures. A patient's self-efficacy is a vital factor and facilitator of adherence in diabetes self-care and treatment regimen (Gans & McPhilips, 2003). Possessing the belief that one has the capacity to adhere to medication, follow a strict diet

and exercise regimen even when there are occasional slip-ups, goes a long way in diabetes management. This reduces diabetes related mortality and complications (Mishalia, Omera, & Heymann, 2011; Schechter & Walker, 2002). Studies have shown that patients who have high self-efficacy were found to adhere to diet regimen and reduce their smoking pattern (Adam & Folds, 2014). A study where in path analysis was conducted to understand the mediating role of self-efficacy in adherence, depression and body mass index (BMI), found that self-efficacy mediated the association between adherence and depression. It also found that those with lower self-efficacy had higher BMI and failure in adhering to treatment (William et al., 2005).

In the context of quality of life of Type II diabetes patients, age, knowledge of diabetes, self-efficacy, and adherence are the main contributors. Age plays an important role, as the timing of being diagnosed with a chronic illness has an impact on various aspects of one's life, depending on the life stage at which the patient is. If the patient is in a life stage where one needs to be highly productive and active, the illness has more impact on them. However, as one's age increases and focus from one's career gets shifted to family bonding and service to the society, the individual gets more comfortable with handling their illness, which no longer seems a big burden to carry. This puts them as ease at disease management and as well as psychological health. Though they may feel weaker physically, they report to have psychological health. According to studies knowledge of illness and in this context diabetes, does play a crucial role in one's disease management (Funnell & Anderson, 2004). Having the necessary information and possessing knowledge helps patients in seeking medical advice, and in encouraging themselves to cope with condition (Alele & Ilesanmi, 2014). Gathering knowledge helps

them assess their susceptibility to the consequences of the illness and increases their efficacy in performing health promoting behaviors (Pongmesa, Li, & Wee, 2009). In the long run knowledge not only impacts adherence but also impacts one's quality of life by increasing healthy coping and reducing distress related to diabetes (Fisher, Hessler, & Glasgow, 2013).

The perceived self-efficacy that one can initiate and sustain behavioral changes helps persons make diabetes specific changes in their diet, physical activity, and disease management in terms of their medication regimen, keeping doctor's appointment, and monitoring blood glucose levels. Studies have shown that factors involving diabetes specific self-efficacy affect one's diabetes related quality of life (Polonsky, 2000). Having high self-efficacy as mentioned earlier, is linked with the physiological response of dealing with stressors in a calm manner, as individuals practice this; it contributes to their positive affect and overall quality of life. It gives them the confidence they are able to control their life situation and take charge of their lives. Studies have shown that selfefficacy significantly predicted quality of life among diabetes patients (Tol et al., 2015).

Adhering to treatment recommendations comes a long way in managing diabetes. Adherence to medication, diet, exercise, leads to good glycemic control, reduces the occurrence of typical diabetes symptoms like tingling in extremities, frequent urination, infections, and the like. Exercise improves one's physical well-being and also has a spillover effect on psychological well-being, improving patient's sense of energy and vitality. Maintaining diet overtime also helps in glycemic control (Tabaei et al., 2004) and puts the patient on steady medication rather than having to alter dosage of medication frequently. This not only reduces the risk of diabetes-related complications but delays the

onset of the same (Nathan et al., 2007). Following regular blood glucose monitoring and getting regular check-ups done, helps the patient monitor their condition closely and maintaining a good glycemic control boosts their confidence and self-efficacy to continue in the same manner. Managing their treatment in an efficient manner reduces the impact of the illness on the patient and improves their health-related quality of life (Vinik & Zhang, 2007). There may be an improvement not just in their health-related quality of life, but in their overall quality of life. With an improvement in their physical functioning and management of the illness, patients with high self-efficacy and adherence also experience psychological, social well-being, and an increase in emotional and cognitive component. Individuals experience better regulation of their physical parameters and increased productivity. This increases their level of independence in terms of their daily chores, capacity to work, mobility and energy and vitality, and a subjective feeling of being fit. Cognitively, their concentration levels increase, helping to excel in their work, which is crucial for their career. Prolonged periods of constant glycemic monitoring, and strict management of the illness, often erodes the emotional strength of a person. This leads to frustration, discouragement, hopelessness, depression and anxiety (Mendlowicz & Stein, 2001). However, in persons who are able to adherence well and whose quality of life is relatively higher, they experience less anxiety and worry related to diabetes, and experience positive affect and happiness. Those who are able to manage their condition well, have self-acceptance, experience a sense of autonomy, and environmental mastery (Kahn & Juster, 2002). They are able to engage in activities that lead to pleasure, personal growth, and fulfillment of human potential and will be able to realize their purpose (Boersma et al., 2005; Seligman, 2002; Waterman, Schwartz, & Conti, 2008).

These positive aspects help them modify the appraisal of the illness and makes coping with it a less intimidating task. This changes the meaning they attach to their illness, the perception of the illness and its outcomes and its impact on their self, their family, priorities of life and future goals. And finally an improvement in quality of life helps them have deeper and better relationships with their family, friends and build a support system for themselves both at home and work (Ferrans, 2005).

## Conclusion

It can be concluded from the findings of this study that there exists a difference in the level of the variables among the three groups that were categorized based on the duration of the illness. Those patients whose duration of illness was above two years and five years had better overall knowledge of diabetes, its symptoms, complications and management than those who were below one year of duration. This indicates that those below one year of duration require more information and knowledge related to the illness in order to cope well. Likewise, patients above two years and five years of duration had better self-efficacy levels than those patients below one year; again indicating that interventions targeted to improve their self-efficacy is required. Findings showed that patients belonging to group II had better adherence to medicine than the other two groups, and group III had better adherence to diet than the second and first groups. This indicates that those below one year of duration had a low adherence level which needs to be addressed. In terms of quality of life, the three groups differed only on the dimension of social burden. Findings show that with greater duration of illness, there was improved quality of life, whereas those below one year of duration had the notion of being a greater social burden to family and friends. This indicates that those patients within one year of duration require more care and help than just medical treatment. They need more information and knowledge, greater encouragement and motivation to improve their selfefficacy and adherence and the assurance of not being a burden to their loved ones.

Findings also showed that demographic variables of age, gender, education and duration of illness, social support, and knowledge of diabetes, self-efficacy, adherence and quality of life are correlated with each other. Though the variable of social support did not have correlation with many variables under study, it showed that those who had greater appraisal support had greater knowledge, those who had greater belongingness support showed greater adherence to keeping doctor's appointment and monitoring their blood glucose levels, and those who had greater self-esteem support had greater adherence to medicine. And there existed a correlation among all the other variables under study.

It can also be concluded that the pathway that leads to adherence is self-efficacy. The findings indicate that though social support and knowledge of diabetes are correlated to adherence, it is self-efficacy that plays a major role in adherence. Findings also indicate that knowledge of diabetes, self-efficacy and adherence, all three play a role in quality of life, with the major role being played by self-efficacy. This indicates that diabetes is a chronic illness, where the main role and effort lies on the part of the patients, where they need to be motivated and consistent in engaging in behaviors to alter their lifestyle and adhere to treatment regimen. However, they do need the support from loved ones, knowledge of the illness, to adhere. Having self-efficacy and consistently adhering to treatment boosts one's quality of life to lead a life of optimal productivity and satisfaction, and getting the bonus of delaying the onset of diabetes-related complications.

### Implications

The findings of the study give an insight into the patient characteristics that are specific to this culture. The Indian culture has the innate quality of being cohesive and closely-knit. Individuals tend to show each other support in times of need. The findings where there was no difference found in social support among the three groups is indicative of the fact that patients possess the required amount of support independent of the duration of illness. However, the study throws light on the lack of knowledge about diabetes, low levels of self-efficacy, adherence and quality of life among newly diagnosed Type II diabetes patients. In these modern times, plenty of information is available on the internet, however, the available information may not reliable or accurate and patients do not know how to channelize the information that is obtained from such sources. Providing accurate and scientific information regarding diabetes can be done in different ways. The role of a Health Psychologist is vital in any hospital setting. They can work in liaison with the hospital authorities and clinicians to organize awareness programs for both patients and their families to provide them with detailed information of the illness, its causes, symptoms, complications and management. Awareness sessions can be planned systematically, so that over three or four sessions, information related to different aspects of the illness can be dealt with in detail, rather than overwhelming the patients with all the information in one session. Receiving such information from persons with credibility increases the impact of the awareness programs. Following which handouts can be provided to supplement the information that given during the awareness program.

The study also brings to the forefront the role of self-efficacy in adherence and quality of life of these patients. Interestingly, departing from the typical theoretical indications that social support plays an important role in adherence, the study shows that though social support is related to few aspects of adherence it does not play a major role in one's adherence to treatment and lifestyle regimen. Likewise, the study also shows that it does not suffice to have high level of education to possess good level of diabetes knowledge. Patients require scientific and systematic knowledge about the different aspects of diabetes. However, possessing high level of education or having good diabetes knowledge did not play a role in adherence. The only major indicator of adherence and quality of life was self-efficacy.

The findings of the study indicate the need to have a psychologist or a health psychologist in diabetes clinics or hospitals as it is beneficial not only in providing information but also in helping patients to undergo interventions related to behavioral change. A health psychologist can help patients sketch out their physical regimen, or changes related to lifestyle in a planned manner. When patients attempt to change their behavior, they usually tend to set high and unrealistic goals, and expect change to occur overnight. Availing counseling sessions with a psychologist or a health psychologist, can help them in setting realistic goals that are suitable to their ability and skill, achieving small goals and then graduating to higher ones. Health psychologists are also equipped in providing techniques based on psychological principles that help patients in their management of the condition. The technique of motivational interviewing, which is one of the CBT techniques, motivates and prepares an individual to execute behavioral change. This being a patient- centered technique, aims to evaluate one's reasons against behavioral change, clarifies their doubts about these changes and helps them in planning various ways to modify their current behavior. This provides the patients some assistance in bringing about behavioral change.

Having an in-house health psychologist is not only beneficial in providing one-toone patient care but also to organize educational programs for masses. As the findings of the study and other studies as well indicate that many patients do not factual information about the illness, organizing these programs can be really beneficial. During awareness programs in a hospital or a clinic, a health psychologist can facilitate in bringing together groups of patients into a peer network or as a peer support group who can either organize to meet occasionally or form groups on social network sites to support each other.

Staying connected to other patients can help them clarify their doubts, or find support in sharing disease management tips, and mainly to perform certain activities together. For example, patients living in a closer neighborhood can work-out together at a common place or do their walking regimes together. Another advantage of being in these groups is that patients can vicariously learn from each other in performing the target behavior. They can also collectively do cost-benefit analysis of a certain behavioral change and help each other in decision making. Forming such groups may give them a sense of belonging, and provide them with tangible support, wherein at any point of need they can be there for each other. They can share recipes that are diabetes friendly or even remind each other of keeping their doctor's appointment. These groups may act as additional motivation and patients can encourage each other to perform self-care behaviors. With a lot of support and encouragement from others, patients may realize that they are not in this alone and that diabetes is a challenge that they can overcome. The study also indicates the importance of adhering to the treatment and the eventually improvement of one's condition that impacts their quality of life. Only when diabetes is well-managed, patients' over quality of life improves.

#### Limitations

• Data were collected from only one city in India, collecting it from different major cities of the country could have made it more representative of the culture. The sample size in each group could have been larger. This would make it possible to perform statistical analyses to assess the impact of the predictor variables on the criterion for a particular group, rather than assess the impact of these variables on

the total sample. This would clearly enable one to see the major indictors that would predict adherence and quality of life specific to each group.

- The age range of the sample could have been smaller or restricted up to 65 years than 75 years. This would have enabled an in-depth study to understand the pattern of the variables in productively rich stages of life.
- The sample could have been divided not only on the basis of duration of illness but also based on life stages. This would help us to understand how individuals adhere and how their quality of life is at different stages of life, while suffering from a chronic condition.

## **Future Directions**

- Future research in this area could have a larger sample size with limited age range or categorize the sample based on life stages along with duration of illness.
- Taking this present research further and developing intervention modules specific for each group of diabetes patients belonging to different duration of illness may benefit the patients. Intervention modules targeted at increasing the patients' knowledge of diabetes, self-efficacy may help in improving their adherence to treatment and quality of life.

• Modules can be designed to bring awareness to the clinicians highlighting their role in patient care would prove to be helpful for the patients. Helping clinicians understand that through their communication with the patients, they can help in delivering important information about diabetes, and providing the needed morale support can go a long way in holistic patient care. The module may also include the immense encouragement that patients receive from the feedback that is given by their clinician regarding their adherence. Reinforcing their adherence to treatment and healthy lifestyle may boost their self-efficacy, helping them to sustain such behaviors in the future.

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