

## **Chapter 1**

### **Introduction**

Diabetes mellitus (DM), especially type 2 diabetes is a serious disease and a cause for growing public health concern in both developed and developing countries. In many countries it is now a leading cause of death, disability and a high health care cost. The World Health Report 1997 paid attention to diabetes: World Health Organization (WHO) warns that diabetes is one of the most daunting challenges posed today by virtue of its frequency, and the cost and suffering imposed by its complications. Also, diabetes is no longer a disease of the affluent; it is now a third world problem and the developing countries will bear the brunt of the diabetes epidemic in the 21st century (MOH Report, 2002)

Diabetes is reaching epidemic proportions in many countries of the world as part of the "globalization" process, and the WHO predicts a tripling of the current prevalence rates by 2025. Diabetes is one of the foremost health challenges facing the world in the new millennium. It has the potential to overwhelm health budgets. Health administrators and health service planners need to heed the warnings as the toll from this serious disease mounts (McGill, 2001). Globally, The World Health Organization (King et al., 1998) suggests an increase worldwide in the prevalence of diabetes in adults of 35% and an increase in the number of people with diabetes of 122%. The developing countries will face an increase of 48% in the prevalence of, and an increase of 170% in the number of people with, diabetes compared to an increase in the prevalence of diabetes of 27% in developed countries, with an increase of 42% in the number of people with diabetes.

The likely burden of diabetes during the first years of the twenty-first century should not be overlooked: figures of 135 million adults with diabetes in 1995 rising to probably 300 million in year 2025 are not far from reality and may even underestimate the magnitude of this major public health problem (Ekoe et al. 2001).

Due to the epidemic nature of diabetes, WHO considered the prevalence of diabetes as a basic health indicator along with measures such as life expectancy, infant mortality rate, immunization coverage and reported cases of selected infectious diseases (MOH Report, 2003).

In Palestine, DM also seems to be a serious health problem among population especially in middle-aged population. This fact could be concluded from global estimates of the WHO and by

extrapolation from similar ethnogenetically population of neighboring countries (MOH Report, 2003). The prevalence rate of DM in Palestine is about 9% in 2002, while the international rate is about 5.2% in the age bracket 20-79, according to International Diabetes Federation (IDF). Gaza study revealed that 65.5% of all diabetics had at least one of the major complications.

The Mortality rate of DM in Palestine has been increased from 7.9 per 100,000 in 1995 to 15.3 per 100,000 in 2002. The age group of  $\geq 60$  years old constitutes about 8.2% from the total deaths in Palestine related to DM, and between 20-59 years about 3.7% from the total deaths, however, in Palestine, there is under-diagnosis and under-reporting in DM as a leading cause of death (MOH Report, 2003).

This research provides a clear picture of the diabetes mellitus in Palestine especially among the refugees. The general purpose of this study is to assess and evaluate the health-related quality of life (HRQOL) of the diabetic Palestinian refugees who live in the refugee camps in Gaza strip. It sights an understanding of how the Palestinian refugees manage their diabetes mellitus and their daily activities under the difficult conditions of the refuge life in the camps; how they evaluate the health services provided for them in the camps and how this impacts the quality of their lives. This research also suggests a comprehensive management plan to minimize the daunting outcomes of diabetes and improve the quality of life of the diabetics in Palestine.

This dissertation is organized into 12 chapters. The first chapter provides an introduction for the study. Chapter 2 provides a clear picture of the global burden of diabetes, the birth of the Palestinian refugee problem, diabetes mellitus among the Palestinian refugees, significance of the problem and significance of the study. Chapter 3 presented briefly the country profile of Palestine including population and demography, Palestinian economy and Palestinian health care system. Chapter 4 provides the theoretical framework for this study. The researcher has used two theoretical models of quality of life: Ferrans's Model, 1990b and Zhan's Model, 1992. These two models are integrated with each other to play a complementary role in establishing the theoretical framework for this study. Chapter 5 provides a detailed literature review regarding the historical background, definition, classification, diagnosis, complications, prevention and management of diabetes. This chapter also presented a clear picture about the diabetes mellitus in developing countries and in the Middle East and how this disease is managed in these countries. Many studies regarding the quality of life and DM and the impact of refugee status on QOL were

presented in this chapter. Chapter 6 introduces the hypotheses, aims and objectives of the study. Chapter 7 addresses the methodology of the study such as: study design, setting of the study, period of the study, study population, sample and sampling techniques, inclusion criteria, data collection procedure, pilot testing, instrument of the study, ethical considerations, constraints and limitations of the study, and the plan of data analysis. Chapter 8 and 9 provide the results of the study. Chapter 10, 11, and 12 discuss the results and provide recommendations, implications and guidelines to be employed in the clinical settings, health planning and future research

We hope that the results of this study will be considered as a motivation to promote evidence-based diagnosis and management guideline of diabetes mellitus suitable for local situation which will help improving patients' clinical outcomes and the quality of their lives and to help primary and secondary health care providers in the early detection of diabetes, proper clinical assessment and delivery of appropriate individualized interventions.

This study will be also a very useful tool for diabetes care providers, researchers and public health experts. It is hoped that those of all disciplines involved in diabetes, regardless of their fields of expertise, will find both interest and practical help from its content.

## Chapter 2

### General background of the study

#### 2.1 Global burden of diabetes

##### In the Globe

The epidemic nature of diabetes continues to affect ever-increasing numbers of people around the world and the number of people with diabetes is expected to double between 2000 and 2030 while public awareness remains low (Wild et al. 2004).

According to International Diabetes Federation (IDF), (2003) and a recent study done by Wild et al. (2004) and undertaken by the World Health Organization (WHO), it is estimated that 177 million people have diabetes in the adult population in the world in 2001 or about 5.2% in the age bracket 20-79, this is an increase over the 2000 estimate of 151 million and an increase from the 1995 global estimation of 135 million people with diabetes which was published in a World Health Organization (WHO) study in 1998. Today, it is estimated that around 194 million people have diabetes in the adult population in the world. The South-East Asian Region has the highest number of people with diabetes mellitus with some 49 million, and its prevalence of 7.5% is the second highest, behind North America (7.8%), and ahead of the Eastern Mediterranean and Middle East Regions (6.4%).

According to WHO (1998), between 1995 and 2025 the number of the adult population affected by diabetes mellitus in developing countries is projected to grow by 170%, from 84 to 228 million people. By 2025, these countries will be home to 76% of all persons with diabetes, as compared with 62% in 1995. In the same period, the developed world will see a 41% increase, from 51 to 72 million people. This more than twofold global increase will occur because of population ageing and growth, as well as from obesity, unhealthy diets and a sedentary lifestyle. These latter factors are closely associated with urbanization and industrialization.

Shocking as they are, these figures represent only clinically diagnosed diabetes, and many more cases of diabetes remain undiagnosed and untreated. In addition, up to one-quarter of western populations have impaired glucose tolerance or the dysmetabolic syndrome, which are considered to represent pre-diabetic states. Type 2 diabetes is appearing increasingly in children and adolescents, and the frequency of diagnosis of pediatric type 2 diabetes is outstripping that of

type 1 diabetes in some areas. The long-term complications associated with type 2 diabetes carries a crushing burden of morbidity and mortality, and most type 2 diabetic patients die prematurely from a cardiovascular event (Zimmet, 2003). Therefore, any measures to prevent or delay the development of diabetes are urgently needed (Uusitupa, 2002).

Of special interest to health economists and planners are WHO's (1998) projections of the age structure of the diabetic population: diabetes is most common among the elderly in many populations, while prevalence rates are rising alarmingly quickly among comparatively young and productive populations in the developing world. If the present trends persist and if no action is taken to address the problem, by 2025 most people with diabetes in developed countries will be aged 65 years or more, while the majority of diabetic persons in developing countries will be in the 45-64 year age group. This means that some 170 million men and women, who will reside in the developing regions of the world in less than 30 years from now, will be suffering from diabetes in their most productive years of life.

### **In Europe**

The rapid increase in diabetes in Europe is a major public health issue. Diabetes is the fourth leading cause of death in Europe, and it carries a 3-4 times higher risk of major cardiovascular complications and is now the commonest cause of heart attack and stroke and a major cause of peripheral vascular disease and peripheral neuropathy leading to a 20 fold higher risk of amputation. The cost of diabetes complications accounts for 5-10% of total healthcare spending in several countries including Belgium, France, Germany, Italy, the Netherlands, Spain, Sweden and the UK. In today's Europe, the average prevalence rate of diabetes is 7.5% and about 60 million people live with diabetes, of whom more than 50% are unaware of their condition leaving them exposed to the risks and costly complications associated with poor control of the illness. In addition to those 60 million people who have diabetes, it is estimated that a further 120 million have pre-diabetes of which 50% will develop diabetes within 5 years. By 2025, the prevalence of diabetes is expected to double in Europe. The prevalence of Type 2 diabetes in France was 3% in 2000. In Ireland, there were around 300,000 people with diagnosed or undiagnosed diabetes. Finland had a population of 5.2 million people and there are 160,000 people with Type 2 diabetes and 40,000 with Type 1. While there was no exact data on diabetes in Poland, the rate was believed to be around 4-6% of the population, with Type 2 diabetes the most common form

(Krohn, et al, 2005 ; Diabetes Federation of Ireland, 2004; International Diabetes Federation, 2004)

In Serbia without Kosovo and Metohia, diabetes mellitus was in the fifth place as a cause of death for decades. In the year 2000, DM was responsible for 2.16% of all causes of death (2.16% in males and 3.12% in females) (Atanaskovic-Markovic et al. 2003). In a population-based study conducted by Hauner et al. (2003) to assess the prevalence of subjects with diabetes mellitus in Germany by retrospectively analyzing routine health insurance data, the results showed that over the 4-year observation period there was a continuous increase in the prevalence of subjects with known diabetes mellitus, from 7.24% in 1998 to 8.79% in 2001. During this period, there was an over-proportional increase in the percentage of subjects treated with insulin, while there was only a moderate increase in the percentage of subjects under oral medication and under dietary treatment, respectively. Another survey (Rathmann, 2003) showed that the total diabetes prevalence in the adult German population in 2000 was 10%, corresponding to 6.3 million people. These data suggest that there is a continuous increase in the prevalence of individuals treated for diabetes in Germany. Therefore, Germany should be listed among the 10 countries with the highest estimated number of people with diabetes in the world (Wild et al. 2004).

This exploding prevalence of diabetes in Europe needs to be recognized as a European public health priority. Member state Health Ministers need to focus on controlling the disease by promoting early stage prevention, early screening and diagnosis and control (International Diabetes Federation, (2004)''

### **In the USA:**

According to American Diabetes Association (ADA) and Centers for Disease Control and Prevention (CDC) (2002):

**Prevalence rate:** Diabetes is becoming more common in the United States. From 1980 through 2002, the number of Americans with diabetes more than doubled (from 5.8 million to 13.3 million). There are 18.2 million people in the United States of America (USA), or 6.3% of the population, who have diabetes. While an estimated 13 million have been diagnosed, unfortunately, 5.2 million people (or nearly one-third) are unaware that they have the disease.

**Incidence rate:** In 2002, about 1.3 million adults between 18 and 79 years of age were

diagnosed with diabetes. From 1997 through 2002, the number of new cases of diagnosed diabetes increased from 878,000 to 1,291,000 (a 47% increase)

**Economic burden of DM in USA:** Direct medical and indirect expenditures attributable to diabetes in 2002 were estimated at \$132 billion. Direct medical expenditures alone totaled \$91.8 billion and attributed to diabetes care, chronic complications, inpatient days, nursing home care, and office visits. Attributable indirect expenditures resulting from lost workdays, restricted activity days, mortality, and permanent disability due to diabetes totaled \$39.8 billion. People with diabetes had medical expenditures that were 2.4 times higher than expenditures that would be incurred by the same group in the absence of diabetes (ADA, 2002).

## **2.2 The birth of the Palestinian refugee problem**

The Palestinian refugee case is the largest and one of the longest standing refugee cases in the world today. More than 6 million persons, comprising around three-quarters of the Palestinian people, and nearly one-third of the global refugee population, remain without a durable solution to their plight. More than half of all Palestinian refugees lack basic day-to-day protection, such as physical security, freedom of movement, and access to employment (The Jerusalem Forum, 2004).

The 1948 war ended in the expulsion of hundreds of thousands of Palestinians from their villages and homes. Israeli settlers moved in to occupy their land and the Palestinian refugees found themselves in refugee camps, or in neighboring Arab countries. Like other refugees, Palestinian refugees who sought safe refuge during periods of conflict assumed that they would be able to immediately return to their homes and villages following the cessation of hostilities.

Masalha (2003) has identified three primary groups of Palestinian refugees: 1) Palestinian refugees displaced in 1948 outside the areas of historic Palestine; 2) Internally displaced Palestinians who remained within the historic Palestine but live in refugee camps; and, 3) Palestinian refugees displaced for the first time in the 1967 war from the West Bank and Gaza Strip to the neighboring Arab countries. For more than five decades Palestinian refugees have been barred from returning to their ancestral villages and homes. Their problem is the greatest and most enduring refugee problem in the world.



### Refugees' destinations

Most refugees did not leave Palestine immediately when their homes were captured by Israel. Instead they left for neighboring parts of the land until those parts were conquered by Israel. Because they were walking, their options were limited.

The West Bank absorbed 38% of the refugees, the Gaza 26% and Lebanon 14%. The remaining 22% was divided between Egypt, Iraq, Syria and Jordan (tables 1 & 2). A minor portion, the upper and middle-class refugees, that fled in the first stage ended up further away from Palestine because they could afford real transportation.

**Table (1): Number & Countries of Palestinian Refugees in 1948-49**

Place of Shelter	Number of Refugees	Percentage
West Bank	375.200	38,23%
Gaza Strip	244.400	26,80%
Jordan	94.000	10,22%
Lebanon	131.600	14,53%
Syria	94.000	10,22%
Iraq	3.000	0,18%
<b>Total</b>	<b>924.200</b>	<b>100%</b>

Source: (Gaza Community Mental Health Programme (GCMHP), 2004).

**Table (2): Total Registered Refugees per Country and Area as at 30 June 2003**

Location		Persons	Babies	Families
<b>West Bank</b>	Jericho	16,656	296	3,659
	Jerusalem	194,182	1,385	44,918
	Hebron	151,395	2,533	31,548
	Nablus	278,521	3,155	60,474
	<b>Field Total</b>	<b>654,971</b>	<b>7,582</b>	<b>143,562</b>
<b>Gaza</b>	Jabalia	161,965	4,602	31,829
	Rimal	145,437	3,451	31,405
	Zeitun	116,681	2,843	30,124
	Nuseirat	106,700	2,659	21,953
	Deir El-Balah	76,406	1,868	16,291
	Khan Yunis	152,812	3,824	33,270
	Rafah	147,220	3,647	29,930
	<b>Field Total</b>	<b>907,221</b>	<b>22,894</b>	<b>194,802</b>
<b>Lebanon</b>	Beirut	48,417	293	13,457
	Mountain	78,400	486	20,724
	Saida	94,840	937	23,152

Continued, table (2),

	Tyre	99,404	1,017	23,292
	Tripoli	54,835	610	12,110
	Beqaa	15,783	153	3,786
	<b>Field Total</b>	<b>391,679</b>	<b>3,496</b>	<b>96,521</b>
<b>Syria</b>	Damascus	321,037	5,634	74,170
	South	22,801	511	5,148
	Homs-Hama	35,883	574	8,773
	North	29,941	560	6,882
	<b>Field Total</b>	<b>409,662</b>	<b>7,279</b>	<b>94,973</b>
<b>Jordan</b>	Amman South	482,736	5,900	87,143
	Irbed	300,981	5,085	57,525
	Amman North	464,782	5,483	87,152
	Zarka	470,268	8,320	85,357
	<b>Field Total</b>	<b>1,718,767</b>	<b>24,788</b>	<b>317,177</b>
	<b>Agency Total</b>	<b>4,082,33</b>	<b>66,039</b>	<b>847,035</b>

Source: (UNRWA, 2003).

### **Refugees' situations**

The experience of refugee life in the UNRWA camps has proven pivotal in the emergence of a distinct camp culture and a Palestinian identity. In "the permanence of transience" that defines refugee life, a new value is placed on older ties of family, clan, and village. Although some refugees possess the economic means to establish themselves in their host countries, many remain in the camps. The situation of refugees in Gaza, the West Bank, and Lebanon, where refugees are denied basic civil rights, is particularly harsh. Population density and unemployment rates within Palestinian refugee camps are among the highest in the world, resulting in chronic poverty, overcrowding, a low standard of living, and a general sense of powerlessness and despair (Global Exchange, 2000).

According to Samaha (1987), the Palestinian refugees are the most protracted of all of the world's refugee crises. One of the important issues related to the Palestinian refugee problem is the consequence of the long-term camp confinement of refugees. The refugee camps have become the symbol of the long-term non-solutions and testimony to the despair of all Palestinians around the world. Researchers dealing with the Palestinian refugees' problem face incomplete and inaccurate data regarding the size and movements of the refugee populations. Not all Palestinians expelled in 1948 are included in UNRWA data because those who are considered self-supporting refugees were excluded. Those were estimated to have constituted some 20% of the exodus in 1948.

## **2.3 Diabetes mellitus among the Palestinian refugees and general population**

### **DM among the Palestinian refugees**

Currently, little baseline data exists on refugee diabetic patients' management and quality of life, especially regarding the Palestinian refugees. Even the Palestinian Health Annual Report (2002) does not mention the incidence rate of DM / 100,000 in Palestine and Gaza strip. This is a very crucial indication that the MOH is in need for real efforts to organize and implement an efficient reporting system in order to reach a unified strategy for the preventive and control of diabetes in Palestine.

By the end of 2003, there were 15,844 diabetic Palestinian refugee patients under supervision of UNRWA's in Gaza Strip, in comparison with 14,726 diabetic patients in 2002.

**The estimated prevalence rate** of diabetes mellitus among Palestinian refugees was 4.3% in 2000, 4.7% in 2001 and 5.2% in 2002. However, these rates relate to the persons treated at UNRWA primary health care facilities and do not reflect the disease burden among the registered refugee population. This might be partly due to the fact that UNRWA's intervention strategy is based on the risk approach and not population-based (UNRWA, 2003).

In 2002, the **reported incidence rate** of new cases of DM among refugees was 244 per 100.000. In 2003, the cumulative reported cases of DM type 1 were 989 cases and 9,339 cases of type 2 were registered in NCD clinics in Gaza Strip; in addition to 6,853 cases who have DM and hypertension. The newly register cases of DM were 2,155 cases (DM type1 was 88 cases, 1,639 cases for type 2 and 428 cases of DM and hypertension). Therefore, the reported incidence rate of new cases of DM among refugees was 242 per 100,000 (MOH Report, 2004). It is noticed that in 2003 the reported new cases of diabetes was less than that in 2002, may be attributed to the difficulties which people face to reach the health institutions related to the strict siege imposed by the occupation.

**Complications:** Gaza study revealed that 65.5% of all diabetic refugees had at least one of the major complications.

**Distribution by age group** shows that, the prevalence rate was increased by increasing the age from 0.03% in ages less than 20 years to 1.36% and 4.47% in ages 40-59 years and 60 years and above respectively. About 19.2% of new diabetic patients were under 30 years, 27% at the age of 40-59 years and 53.8% at age 60 years and above.

**Distribution of cases by type of DM** shows that, type 1 DM among new registered cases was 20.9% and 4.1% among all cases, while type 2 DM among new registered cases was 68.7% and 52.3% among all cases.

**Distribution of cases by management** shows that, about 19.6% of all diabetics were managed by insulin treatment, only 15.5% are treated with a combined therapy (insulin and oral hypoglycemic agents, OHA), oral anti-diabetic agents is 60.8%, and diet control is 4.1%.

### **Diabetes mellitus among the Palestinian population**

According to MOH Annual Health Reports, 2000, 2001, 2002, 2003, and 2004:

#### **Prevalence of DM**

The prevalence rate of DM in Palestine is about 9% in 2000. It is around the reported prevalence rate in Egypt and Tunisia (9%) and less than in Saudi Arabia (12%) and Oman (13%) (MOH, 2004).

#### **Incidence of Diabetes Mellitus**

The reported incidence rate (new registered cases) of DM in West Bank is 123 per 100,000, 227.9 per 100,000 and 161 per 100,000 in 2000, 2002, and 2003 respectively. Data from Gaza strip is not available.

#### **Distribution by age**

Distribution of incidence rate of DM by age group shows that, in 2000, the onset age groups of DM are 15-19 years, and 0-4 years in 2000 and 2002 respectively, and increases gradually by age. In 2000, the high incidence rate is reported since the age 50 years old, while in 2002, the high incidence rate is reported since the age of 20-29 years at the rate of 33 per 100,000 to reach 1,988 per 100,000 in the 60 years and above. In 2003, in West Bank, distribution of incidence rate of DM by age group shows that, the peak onset started since the age of 25-34 years at the rate of 43.1 per 100,000 to reach 1,310.2 per 100,000 among the age group of 55-64 years and 1,335.0 per 100,000 at the age of 65 years and over. Data reported from Gaza strip showed that out of total new reported cases in 2003 about 37.9% was among age group of 50-64 years and 11.5% among age under 30 years.

#### **Distribution by sex**

The distribution of type 2 diabetes by sex of patients in 2000 is about 35.4% in males and 64.6% in females, while in 2003, males constitute about 40.2% vs. 59.8% for females. The higher

incidence of type 2 diabetes among females might be explained by the higher prevalence of obesity, multiparity and more attendance of females to health centers than males

#### Risk Factors

The Palestinian annual health reports (2000, 2003) identified only one risk factor among the Palestinian diabetics, which is the obesity. In 2000, the incidence of diabetic patients with obesity is 44.5% in males and 55.6% in females; while in 2002, the incidence of diabetic patients with obesity is 60.8% (42.3% in males and 72.4% in females). Regarding the other risk factors such as older age, family history of diabetes, prior history of gestational diabetes, impaired glucose tolerance, physical inactivity...etc., there is no information or statistics available about them.

#### Complications

In 2000, about 17% of type 2 diabetes patients who are followed by governmental health clinics are suffering from major complications: retinopathy 19.2%, Nephropathy 8.1%, Neuropathy 40.4%, cardiovascular 26.3% and peripheral vascular diseases 6%. Further data about the years 2002 or 2003 is not available.

#### Mortality rate:

In Palestine, there is under-diagnosis and under-reporting in DM as a leading cause of death. The mortality rate of DM has been increased from 7.9 per 100,000 in 1995 to 15.3 per 100,000 in 2002. In 2003, in age group of 20-59 years and  $\geq 60$  years it is the 8th and 7th leading cause of death respectively. Above 60 years old about 8.2% from the total deaths in Palestine, and between 20-59 years about 3.7% from the total deaths (MOH Annual Health Reports, 2000-2004).

**Conclusion:** According to other non-governmental surveys (Abdul-Rahim, & Husseini , 2001; Abdul-Rahim, & Bjertness 2001) conducted to determine the prevalence of diabetes in Palestine, the prevalence rate ranges from 11.3% to 13.9%. All of these studies in addition to the figures reported from The Palestinian annual health reports (2000-2003) indicated the rapid rise in non-communicable diseases especially diabetes which should be taken by the authorities as a major public health concern.

## **2.4 Significance of the problem**

By the end of 2003, there were 15,844 diabetic Palestinian refugee patients under supervision of UNRWA's in Gaza Strip, compared with 14,726 in 2002 (Health Status in Palestine, 2002 & 2003) and 5,529 registered diabetic patients in 1992 (UNRWA Annual Report, 1993). Gaza study

revealed that 65.5% of all diabetics had at least one of the major complications and only 39.7% had acceptable glycemic control. Self-monitoring of blood glucose (SMBG) is not available for most of patients. It is estimated that only 12% of patients have this facility due to economic situation. And even the mortality rate of DM has been increased from 7.9 per 100,000 in 1995 to 15.3 per 100,000 in 2002. Diabetics aged  $\geq 60$  years old constitute about 8.2% from the total deaths in Palestine, and between 20-59 years about 3.7% from the total deaths.

According to UNRWA Report 2001, in Jordan, for example, there were about 22.5 thousand registered refugee patients with diabetes in 2000 compared to 10.5 thousand registered in 1994 and 5 thousand in 1990 (UNRWA Annual Report, 2001).

In a study (2000) conducted at all UNRWA primary health care facilities in Lebanon Field to assess the quality of care of diabetes mellitus and hypertension, 2202 records of diabetic and hypertensive patients were reviewed. Yusef found that 41.9% of all the surveyed patients had at least one of the late complications: 46.3% of type 2 diabetes patients and 37.8% of patients with only hypertension (Yusef, 2000).

These increasing figures of the Palestinian refugees who are suffering from DM and the associated complications are in need for special efforts to understand how DM affects their daily lives and how the difficult conditions of their refuge life affect the management of diabetes.

## **2.5 Significance of the study**

We know little about the day-to-day experiences of living with and managing diabetes in a refugee camp and the quality of the diabetic refugees' life. No previous studies about Palestinian refugees or about their management of chronic diseases such as diabetes have been located in the literature. A second world health organization (WHO) study Group (1985) emphasized that often the impact of diabetes is not fully acknowledged and should attract more attention from health care professionals and planners.

The research on quality of life has been emphasized by the United Nation Education Science Cultural Organization (UNESCO, 1977) with projects that develop research designs and instruments that are likely to stimulate QOL research in regions that have no research traditions in this field. Such research takes into account the fact that individuals and groups not only experience life quality but also participate in creating their life quality. Research studies about QOL of a person managing a chronic condition could be policy-oriented and provide information

and clarification to the public, and have relevance to decision makers (Milbrath, 1979). In this regard, WHO has developed a quality of life assessment tool called World Health Organization Quality of Life Questionnaire- short version (WHOQOL-BREF). This initiative arose from a need for a genuinely international measure of quality of life and a commitment to the continued promotion of a holistic approach to health and health care.

The study of how Palestinian refugees define and manage diabetes and how this impacts on their life is useful for health workers to help them improve their management (styles) behaviors, their QOL and the quality of care offered for these refugees. This study identifies the important variables needed to establish the basis for future research among the refugees with chronic diseases in general, and with diabetes in particular. It also expands the limited knowledge and research base about the refugees and how they define and manage the chronic disease of diabetes, and how this chronic disease affects their QOL. The results of this study will facilitate provision of adequate and appropriate care for refugees with diabetes based on their assessed needs and available resources.

Few data exist and no previous studies have been located in the literature about the quality of life of the diabetic refugees in Gaza strip. Moreover, there are no studies talked about how the Palestinian refugees in Gaza strip manage their chronic diseases such as DM under the difficult conditions of the refuge life in which there are lack of medical facilities, transportation difficulties to reach the health centers and hospitals, too long curfews, enormous stress, poverty and malnutrition, etc.

Based on that, this study is considered the first step to initiate epidemiological database necessary for rebuilding the destroyed Palestinian health system, improving health status, effectively allocating the limited health resources and providing health prevention, promotion, and restoration for DM not only in Gaza strip but also in all fields where the Palestinian refugees live such as West Bank, Lebanon, Syria, Jordan, Egypt and Iraq.

This study also will be a very useful tool for DM care providers, researchers and public health experts in Palestine. It provides a clear picture of the characteristics of the epidemic nature of DM, its complications, and its management not only among the Palestinian refugees but also in the Middle East and the developing countries. It is hoped that those of all disciplines involved in DM, regardless of their fields of expertise, will find both interest and practical help from its content.

## **Chapter 3**

### **Country Profile**

#### **3.1 Population and Demography**

##### **3.1.1 Geographical Distribution**

Palestinian National Authority (PNA) territories comprise two geographically separated areas: West Bank and Gaza Strip. West Bank lies within an area of 5,800 sq. km<sup>2</sup> west of the Jordanian river. It has been under Israeli Military Occupation, together with East Jerusalem since June 1967. West Bank is divided into four geographical regions. The Northern area includes the districts of Nablus, Jenin and Tulkarem; the Centre includes the districts of Ramallah and Jerusalem; the South includes Bethlehem, Al-Khaliel district; and the Jordan valley including Jericho. Many areas of West Bank have diversified communities. There are observable differences in life styles and living conditions not only among classes or socioeconomic levels and religious affiliations, but also among urban, rural and refugee camp communities with their respective subdivisions. Up to sixty percent of the population lives in approximately 400 villages and nineteen refugee camps, and the remainder in urban refugee camps and cities of which Nablus, East Jerusalem and Al Khaleil are the most populous.

Gaza strip is a narrow piece of land lying on the coast of the Mediterranean Sea. Its position on the crossroads from Africa to Asia made it a target for occupiers and conquerors over the centuries. The last of these was Israel who occupied the Gaza strip from Egyptians in 1967. Gaza Strip is very crowded place with an area of 360 sq. Km<sup>2</sup>; the population is mainly concentrated in the cities, small villages, and eight refugee camps that contain two thirds of the population. The main income source for Gaza population was working in Israel, in addition to the poor agriculture products that have to be exported via Israel. Part of the refugee population was moved from camps to new areas. A part from the weak economic situation and its consequences for the public health, the population of Gaza as all Palestinian population has lived through several consecutive wars (1948, 1956, 1967) and long stressful periods (the Israeli occupation). During the years from 1987 to 1992, Intifada - the Palestinian uprising- erupted spontaneously. It was led by children and youth, who chose to face the Israeli occupation with stones, burning tires and roadblocks. Since September 29, 2000, Al-Aqsa Intifada has been erupted to face Israeli neglecting of Palestinian national rights.



### **3.1.2 Executive Summary**

The estimated number of Palestinians all over the World by the end of 2003 is 9.7 millions and they will increase to 6.2 million in mid 2010 and 8.2 million in 2020.

- The population in Palestine is estimated 3.7 million at the end of 2003, out of them 2.3 million (63.3%) in West Bank and 1.4 million (36.7%) in Gaza Strip.
- According to the 1996 data; about 2.8 million Palestinians are living in Jordan, 42.5% of them under 15 years, and in 1999 the total fertility rate was 4.6 births per woman.
- In 2003, about 436,157 Palestinians living in Syria; 36.7% of them are under 15 years, and the total fertility rate was 3.5 births per woman.
- In 2003 about 415,066 Palestinians living in Lebanon show that 36.4% of them are under 15 years, the total fertility rate was 3.5 births per woman.
- In 2003 about 1.1 million Palestinians living beyond the green line, 41.5% of them are under 15 years and the total fertility rate was 4.6 births per woman.
- The number of Palestinians living in the other Arab countries was 595,000 (6.2%).
- There are 236,000 in the United States of America and 301,000 in other foreign countries.
- 42.6% of the Population in Palestine is Refugees.
- 46.0% of the Population in Palestine is under 15 years.
- Marriages declined by 3.8% in 2002 compared with 1997.
- The numbers of divorces in Palestine are fluctuating between 1.2% and 0.9% (1997- 2002).
- The median age in Palestine is 16.7 years.
- Crude birth rate in Palestine dropped from 42.7 births per 1000 population in 1997 to 27.2 in 2003
- The crude death rate in Palestine declined from 4.8 deaths per 1000 population in 1997 to 2.7 in 2003.
- Population natural increase rate is 2.4% in Palestine in 2003.
- Life expectancy in 2003 is 70.7 years for males and 73.8 years for females.

### **3.1.3 The Palestinian population in Palestine**

The population of Palestine is estimated to 3.7 million at the end of 2003; 2.3 million (63.3%) in West Bank and 1.4 million (36.7%) in Gaza Strip. According to the distribution of the population by Governorates, AL khaleil Governorate has the highest rate of population at 13.9% of the total population, followed by Gaza Governorate 13.0%; AL Quds Governorate comes third with

10.8%. On the other hand, Jericho Governorate has the lowest rate of population at the end of 2003 at 1.1%.

#### Percentage of the refugees

According to the labor force survey 2003, 42.6% of the population in Palestine is refugees. They estimates 1.6 million at the end of 2003 thereof 695,000 (29.4%) in West Bank and 897,000 (65.5%) in Gaza Strip.

#### Age groups

According to the most recent estimates, 46.0% of the population in Palestine is under 15 years; 44.1% in West Bank and 49.0% in Gaza Strip. The percentage of Palestinians who are above 65 years in Palestine is 3.1%; this figure reached 3.3% in West Bank and 2.7% in Gaza Strip.

#### Sex ratio in Palestine

The estimated number of males in Palestine at the end of 2003 is 1.89 million compared with 1.84 million females; the sex ratio is 102.7 per 100 females.

In West Bank, males' totals 1.20 million compared with 1.17 for females; the sex ratio is 102.8 per 100 females.

In Gaza Strip, the males' total is 694 thousand compared with 677 thousand females; the sex ratio is 102.5 per 100 females.

#### Percentage of the females' in Palestine aged (15-49) Years

The number of females in Palestine at the age group of 15-49 is estimated to 833,920 (45.2%) of the total number of the females at the end of 2003, out of which 542,258 in West Bank (29.4%) and 291,662 (15.8%) in Gaza Strip.

#### High Dependency ratio in Palestine

Data indicate that dependency ratio in Palestine dropped from 101.3 in 1997 to 97.0 in 2003 where it declined from 94.7 in 1997 to 91.3 in 2003 in West Bank and from 114.5 in 1997 to 107.8 in 2003 in Gaza Strip.

#### Declining crude birth rate in Palestine

The crude birth rate in Palestine dropped from 42.7 births per 1000 population in 1997 to 27.2 in 2003. However, there are regional discrepancies where the crude birth rate in West Bank decreased from 41.2 births per 1000 population in 1997 to 25.1 in 2003; whereas in Gaza Strip, where the rate slightly dropped from 45.4 in 1997 to 30.8 in 2003.

### Declining crude death rate in Palestine

The crude death rate in Palestine declined from 4.8 deaths per 1000 population in 1997 to 2.7 in 2003. There is a slight difference between West Bank and Gaza Strip. In West Bank, the crude death rate dropped from 4.9 in 1997 to 2.4 in 2003, where it dropped from 4.7 to 3.2 in Gaza Strip for the same period. These results indicate that there is an improvement in the living standards, health services, and health awareness among people.

### Population natural increase rate

Population natural increase rate is 2.4% in Palestine in 2003. These rates reach 2.3% in West Bank and 2.8% in Gaza Strip. The declining mortality rate and increasing fertility rate would lead to a high rate of natural increase in the population. Subsequently, proper economic and social policies are required to cope with such increase. Palestinian Central Bureau of Statistics (PCBS) estimated the natural increase rate in Palestine at 3.6% (3.4% in West Bank and 4.0% in Gaza Strip) between 1997 and 2003.

### High fertility rate in Palestine

The fertility rate in Palestine is high compared to those dominant in other countries, which may be due to early marriage especially among females, the desire to have many children, and the prevailing traditions of the Palestinian society. However, indicators shown that fertility rate started to decline toward end of the 20 century. The total fertility rate in Palestine was 3.89 (3.4 in West Bank and 4.7 in Gaza Strip). It declined from 4.39 in 1999 (4.1 in West Bank and 5.0 in Gaza Strip) to 3.89 in 2003.

### Life expectancy

The decline in the mortality rate in Palestine led to longer life expectancy to reach 70.7 years for males and 73.8 years for females in 2003. There are regional discrepancies; life expectancy in West Bank is 71.2 years for males and 74.3 years for females compared with 70 years for males and 73.2 years for females in Gaza Strip. The improved health situation and the gradual decline in the infant and child mortality rate contributed to longer life expectancy.

## **3.2 Palestinian economy**

According to Palestinian Monetary Authority (PMA) the Gross National Product (GNP) in Palestine has been subjected to high fluctuations during the last five years. GNP was 5,454 million US\$ in 1999 and decreased to 3,705 million US\$ in 2003. Gross Domestic Production (GDP) was 4,517 million US\$ in 1999 and decreased to 3,257 million US\$ in 2003. Gross

National production per capita (GNP/capita) was 1,806 US\$ in 1999 and decreased to 1,020 US\$ in 2003. Gross Domestic Production per capita (GDP/capita) was 1,496 US\$ in 1999 and decreased to 896 US\$ in 2003. The number of workers in Israel decreased from 135,000 in 1999 to 50,000 in 2003. And the workers in Palestine also increased from 453,000 in 1999 to 474,000 in 2003 due to the political situation and recurrent crisis in Palestine. In 2003, the PMA reported that the unemployment rate is sharply increased from 11.8% in 1999 to reached 31% with constant fluctuation during the last five years due to political situation, and the occupation's practices including closure of Palestinian regions and cities, and other constraints activities (MOH, 2004).

### **3.3 Environmental Situation**

**Water:** scarcity and deterioration quality and quantity of the Palestinian water resources may be the most crucial environmental problem and environmental challenges facing the Palestinian people and the Palestinian National Authority at the dawn of the 21st century. Currently, our use of the West Bank water resources is highly restricted by the Israelis, although we have the rights in the surface water of river Jordan but they are denied our access to this resource. So the typical form in West Bank is mainly to collect water from the roofs of the buildings during winter and store them in underground holes dug for this purpose, while the main source of water in Gaza Strip is the groundwater from the coastal aquifer. In addition the utilization of the Israeli settlers to Palestinian wells around the border of Gaza Strip and the over-pumping of the wells within the settlements which accelerated the increase of salinity and depletion of the groundwater as a result of seawater intrusion into the coastal aquifer system. Eventually, urgent pollution control should take place since the aquifers in the West Bank and in the Gaza Strip are almost suffering from salinity and nitrogen pollution. The percentage of households connected by water networks are 84.8% in Palestine (80.7% in WB and 93.3% in GS).

**Wastewater:** It is reported that 53.5% of the population in the Gaza Strip are connected to sewer networks and about 34% in West Bank, while cesspits and septic tanks receive the rest. Thus, there is a great need to put a high priority to set up an effective wastewater management system in Palestine.

**Solid Waste:** Disposal of solid waste at open dumpsites is the common disposal method currently used in West Bank, while in Gaza Strip many small uncontrolled dumping sites have been closed and there are currently two controlled landfills in operation (Gaza City and Deir El-Balah). The

improper handling of solid waste and infiltration of wastewater is a major cause of deterioration of water quality, land degradation, and air pollution.

Medical waste in Palestine is not given the right concern. The amount of medical waste generated in health care institutions was estimated to be 8 tons/day and 2.67 kg/patient/day in Shifa hospital. There is no separation of different type of waste except for sharps which are collected mainly (78.6%) in special boxes donated by WHO. There is no system of color-coding bags and there are no storage rooms for medical waste. In Primary Health Care (PHC) clinics, medical waste is disposed with domestic waste without any special treatment, or it is burned manually in open air, and in hospitals it is burned in hospital incinerators. There is no control on incinerator emissions and no measurement of pollutants emitted. Inadequate practices are due to lack of system, inaccessibility of necessary facilities and supplies, lack of coordination between ministries and lack of knowledge among people especially health workers.

**Air pollution:** Transportation contributes about (40-50%) to the air pollution in West Bank and it is more than (50%) in Gaza Strip, in addition to high density of traffic and the high number of old cars. Furthermore, industry is one of the main sources of air pollution. On the other hand, Israeli industrial estates in the settlements generate relatively high levels of air pollution, compared to the industrial estates in Israel (MOH, 2000-2003).

### **3.4 Palestinian Health Care System**

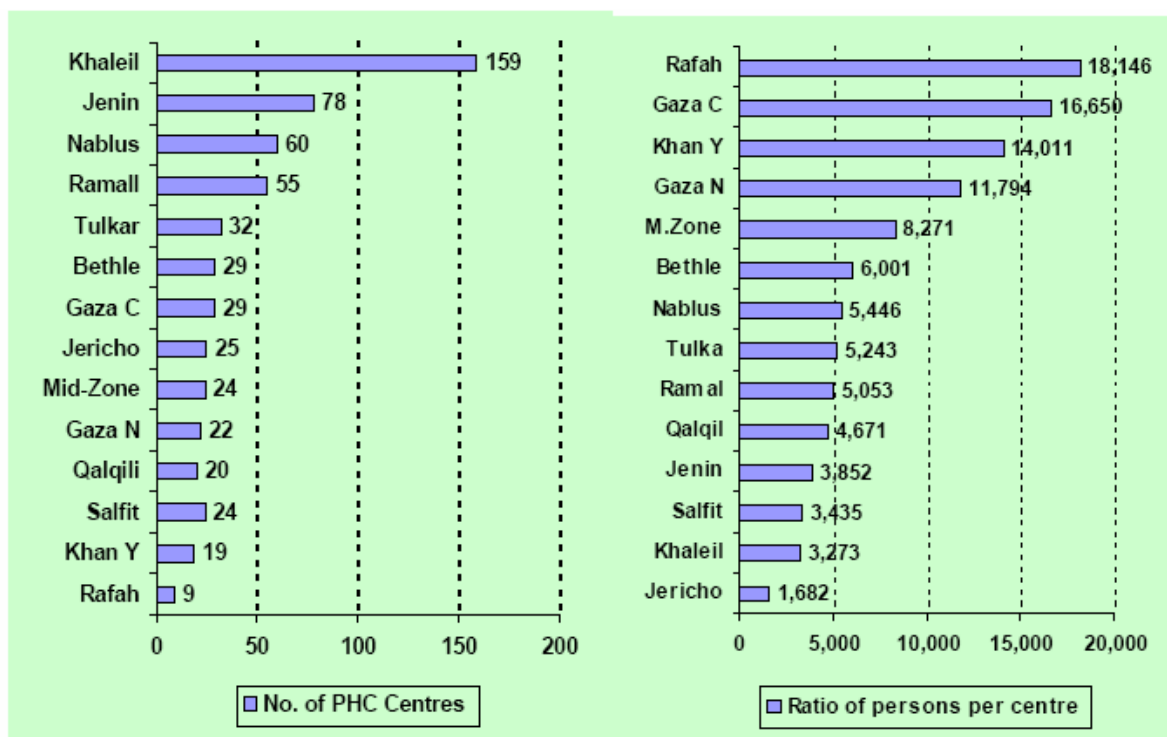
#### **3.4.1 Primary Health Care (PHC) Centers in Palestine**

The total number of registered PHC centers in Palestine is 619 (103 in Gaza Strip and 516 in West Bank). Distribution by provider shows that, there are 391 centers owned and supervised by MOH with a high percentage of 63.1%, 51 centers by UNRWA (17 centers in Gaza Strip and 34 in West Bank) with a percentage of 8.2% and NGOs have 177 centers with a percentage of 28.6% of the total centers.

According to the UNRWA, the ratio of refugee per center is 30,482 in Palestine, (52,283 in Gaza Strip and 19,581 in West Bank). UNRWA has offered health services free of charge for all refugees and plays a distinguished role in the vaccination program in cooperation with MOH, in addition to curative services, antenatal and postnatal care and other specialized services.

According to the MOH, the overall ratio of persons per center in Palestine was 5,746 in 2000 and 5,628 in 2003. In Gaza Strip, due to the high population density, the ratio of persons per center

was 13,304 and ranged from 8,271 to 18,146 persons, compared with 4,096 persons per center in West Bank (figure 1).



**Figure (1): Distribution of total PHC centers and the ratio of persons per center by governorate in Palestine, 2003**

Source: (MOH, July 2004)

### 3.4.2 Laboratories and Blood Banks

The laboratory services in the MOH are offered to Palestinian people at three levels: Central, Intermediate and Peripheral. There are 85 peripheral, 17 intermediate and 4 central laboratories in MOH. There are 220 official and 76 non official technicians running the laboratories services in the intermediate laboratories with an annual average workload of 13,247 tests per technician (14,034 in WB and 12,726 in GS). On the other hand, 117 official and 44 non-official technicians work in the peripheral laboratories with annual average workload of 6,875 tests per technician (6,954 in WB and 6,783 in GS).

### 3.4.3 Hospitals in Palestine

In Palestine, there are 78 hospitals. The population/hospital ratio is 47,922. The average bed capacity per hospital is 59.99 beds. In Gaza Strip (GS), there are 24 hospitals making (30.77%).

The population/ hospital ratio is 57,098. The average bed capacity per hospital is 79.88 beds. In West Bank including Jerusalem, there are 54 hospitals making (69.23%). The ratio of population per hospital is 43,844. The average bed capacity per hospital is 51.15 beds.

### Hospital Beds

Including the mental hospitals, the total number of beds in Palestine is 4,679. The population/bed ratio is 799 in all over Palestine including Jerusalem. In Gaza Strip, the ratio is 715 while in West Bank it is 857. The ratio of Beds/ 10,000 populations in all over Palestine is 12.52 beds. In Gaza Strip the ratio raises up to 13.99 beds, while in West Bank it decreases to 11.67 beds. In Palestine, the comparison between hospital beds in 1999 and 2003 shows a tremendous increase in bed capacity from (3,386 in 1999) to (4,679 in 2003). MOH is responsible for most of the quantitative growth in hospital beds, with an increasing percentage of 38.2% in comparison with 1999.

### Hospital Services Providers

The secondary health care delivery system is a mixture of a public, non-governmental (NGO's), UNRWA and private sectors with a developing governmental insurance (see table 3). MOH is responsible for a significant portion of the secondary healthcare delivery system and some of the tertiary care.

**Table (3): Comparison between beds by health providers in 1999 and 2003**

Provider	1999			2003			% of expanding
	WB	GS	Palestine	WB	GS	Palestine	
MOH	1,009	896	2,005	1,152	1,462	2,614	30.4
NGOS	1,094	314	1,408	1,073	416	1,489	5.8
Private	258	36	294	479	39	518	76.2
UNRWA	38	0	38	58	0	58	52.6
<b>Total</b>	<b>2,179</b>	<b>1,207</b>	<b>3,386</b>	<b>2,762</b>	<b>1,917</b>	<b>4,679</b>	<b>38.2</b>

### Hospital Categories

In Palestine, hospitals can be classified into four categories (table 4): General hospitals: provide basic secondary health care services to a local geographic area. Some of those hospitals are large enough to provide a full compliment of advanced secondary and to some extent tertiary health care services. The specialized hospitals provide full compliment of advanced secondary and tertiary services in one specialty domain. The maternity hospitals are designated to serve mothers. The rehabilitation centers or hospitals are assigned to provide full band of rehabilitative services.

In 2003, there are 39 general hospitals with 2,812 beds in addition to 14 specialized hospitals with total bed capacity of 1,243 beds and 21 maternity hospitals at a total bed capacity of 469 beds and finally 4 rehabilitation centers with a total bed capacity of 155 beds. MOH managed to provide a balanced pool of beds. It owns and operates 55.2% of the general hospital beds, 73.1% of the specialized hospital beds, and 35.6% of the maternity hospital beds.

**Table (4): Distribution of hospital beds by provider and specialty, Palestine 2003**

Provider	General beds		Specialized beds		Rehabilitation beds		Maternity beds	
	NO	%	NO	%	NO	%	NO	%
MOH	1,553	55.2	909	73.1	0	0	167	35.6
NGOs	993	35.3	182	14.6	155	100	82	17.5
Private	208	7.4	152	12.2	0	0	220	46.9
UNRWA	58	2.1	0	0.0	0	0.0	0	0.0
<b>Total</b>	<b>2,812</b>	<b>100</b>	<b>1,243</b>	<b>100</b>	<b>155</b>	<b>100</b>	<b>469</b>	<b>100</b>

#### 3.4.4 Human Resources

In Palestine, the health providers (MOH, NGOs, MSP and UNRWA) employ 16,935 permanent employees, 8,882 in WB (52.4%) and 8,053 in GS (47.6%). Out of them 9,069 (53.6 %) work in MOH, 5,632 (33.2%) in NGOs, 1,157 (6.8%) in UNRWA and 1,077 (6.4 %) in MSP. Out of the total employees, 11,933 (70.5%) are health professionals. They are distributed by specialty: 3,093 physicians, 293 dentists, and 329 pharmacists with a ratio per 10,000 persons of 8.3, 0.8 and 0.9 respectively, in addition to 4,905 nurses, 574 midwives and 2,739 paramedical, with a ratio per 10,000 persons of 13.1, 1.5 and 7.3 respectively. The rest of health employees are 5,002 administrators and workers with a ratio of 13.4 per 10,000 persons. 128 health workers work in Palestinian health facilities with a ratio of 0.3 per 10,000 persons.

#### 3.4.5 Health Finance

According to Ministry of Finance (MOF) estimation, the third year of Al Aqsa Intifada has witnessed a further steep decline in all Palestinian economic indicators. Gross National production (GNP) was 5,274 million US\$ in 2000 and decreased to 3,705 million US\$ in 2003. Gross Domestic Production (GDP) was 4,442 million US\$ in 2000 and decreased to 3,257 million US\$ in 2003. GNP and GDP per capita in 2003 were 1,020 and 896 US\$ respectively. Unemployment rate stands at 31% of the workforce.



### National Health Expenditures

In a study by the World Bank (1997), they estimated the per capital health expenditures in West Bank and Gaza Strip at 122 US\$ in 1996, which means 8.6% of the GDP. In 1997, the national health expenditure of GDP ranged between 6.6 % and 8.2%. MOH expenditure of GDP was 3.2% and 3.02% in 2002 and 2003 respectively.

In 2003, about 18% of all MOH-health care expenditures in Palestine were on medications and medical disposables. About 55% of the MOH budget and nearly half of all expenditures in UNRWA and the non- governmental sector consist of wages and salaries and other forms of employee remuneration. Finally, about 13% and 14% of total MOH health expenditures were on treatment abroad and other operating cost respectively. As the actual MOH health care expenditure in Palestine was 98,421,543 US\$ in 2003, therefore the annual budget of MOH per capita was 26.3 US\$ at average exchange rate.

### **3.4.6 The Governmental Health Insurance (GHI)**

The enrolment in GHI grew from 50 % in 1998, to 53.2% in 1999. It declined to 34% in 2000, 31% in 2001, 34.6% in 2002, and 38.6% in 2003. The decrease in enrollment in GHI since 2000 was due to the impact of current crisis on Palestinian community. In Palestine, MOH provided free of charge health insurance to about 189,934 family in 2001, 207,434 family in 2002 and 95,449 family in 2003.

#### **Types of Participation:**

##### 1. Compulsory:

The families' participation from this group was about 19.3% in 1995 of the total insurance participation, 19.3% in 2001, 17% in 2002, and 28.2% in 2003. The revenues was 20.9% from the total governmental insurance revenues in 1993, increases gradually to 24.8% in 1995, reached to 35.4% in 2000, 57% in 2001, 60.4% in 2002 and 56.6% in 2003. This indicates that GHI is still alive due to this type of compulsory insurance of governments, municipalities and retired employees.

##### 2. Voluntary:

Since the year 1995, there was a gradual decline in the number of insured families in the voluntary type (24% in 1995, 5% in 2000, and 2.8% in 2001 to 2.3% in 2002 and 1.2% in 2003 of the total insurance participation). This is due to deterioration in Palestinian economy. The

percentage of the revenue collected from this group to the total government health insurance revenues decreased from 16% in 1995, 5.1% in 2000, and 4% in 2001 to 2.4% in 2002 and 2% in 2003.

### 3. Workers in Israel:

It represented nearly 19% of the total participants in the years 1995-1998 and reached to 20.4% of participants in 1999, 19% in 2000 (13% in WB Vs 30% in GS), only 0.9% in 2001, 1.5% in 2002 and 4.9% in 2003. This group showed the highest decline in the percentage of its revenues from 40.6% in 1995 to 37.7% in 1998, 25.3% in 2000, arrived to 5.3% in 2001, 6.9% in 2002 and 9.8% in 2003. This is mainly affected by the closures and the current crisis.

### 4. Social Welfare:

This group has increased from 20,742 family, represents 20.5% of the total participants in 1998, to 29,907 family represents 17% of the total participants in the year 2000 arrived to 41,964 family represent 12.2% of the total participants in 2001, 40,741 family represent 10.1% of the total participants in 2002 and 45,303 family represents 19.2% of the participants in 2003. The Ministry of Social Welfare paid 18% of total revenue in 1995, 14.7% in 1998 and 17% in 2000 respectively, 21.8% in 2001, 20.9% in 2002 and 19.5% in 2003 of the total insurance revenue.

### **3.4.7 Health projects**

In 2003, 48 health projects still continue their activities in the health sector with a total budget of 126.1615 million US\$. These projects are 22 soft projects in terms of equipments, materials and technical assistants with a total budget of 78.99 million US\$, in addition to 26 projects in the construction field with a total budget of 47.172 million US\$.

#### Distribution by region:

- 19 projects were conducted in both of West Bank and Gaza Strip with a total budget of 68.787 million US\$.
- 12 projects were conducted in West Bank only with a total budget of 28.27 million US\$.
- 17 projects were conducted in Gaza Strip only with a total budget of 29.10 million US\$.

### **3.4.8 Palestinian Health Information Center (PHIC):**

MOH efforts to unify the Information Technology (IT) processes of the Ministry across the entire country are so very important. PHIC is a natural extension of Health Management Information System. It has been formulated since the establishment of Palestinian National Authority. As a

result of natural development, the decision had been taken to establish PHIC. PHIC includes information technology department and information department.

The strategy for (PHIC) is:

- Designing a national health database.
- Improving the using of a health data dictionary and update it regularly.
- Improving the implementation of clinical health information system in hospitals and PHC centers.
- Developing advanced medical informatics applications, including electronic medical records and telemedicine.
- Developing an integrated telecommunications infrastructure (MOH, 2000-2003).

## **Chapter 4**

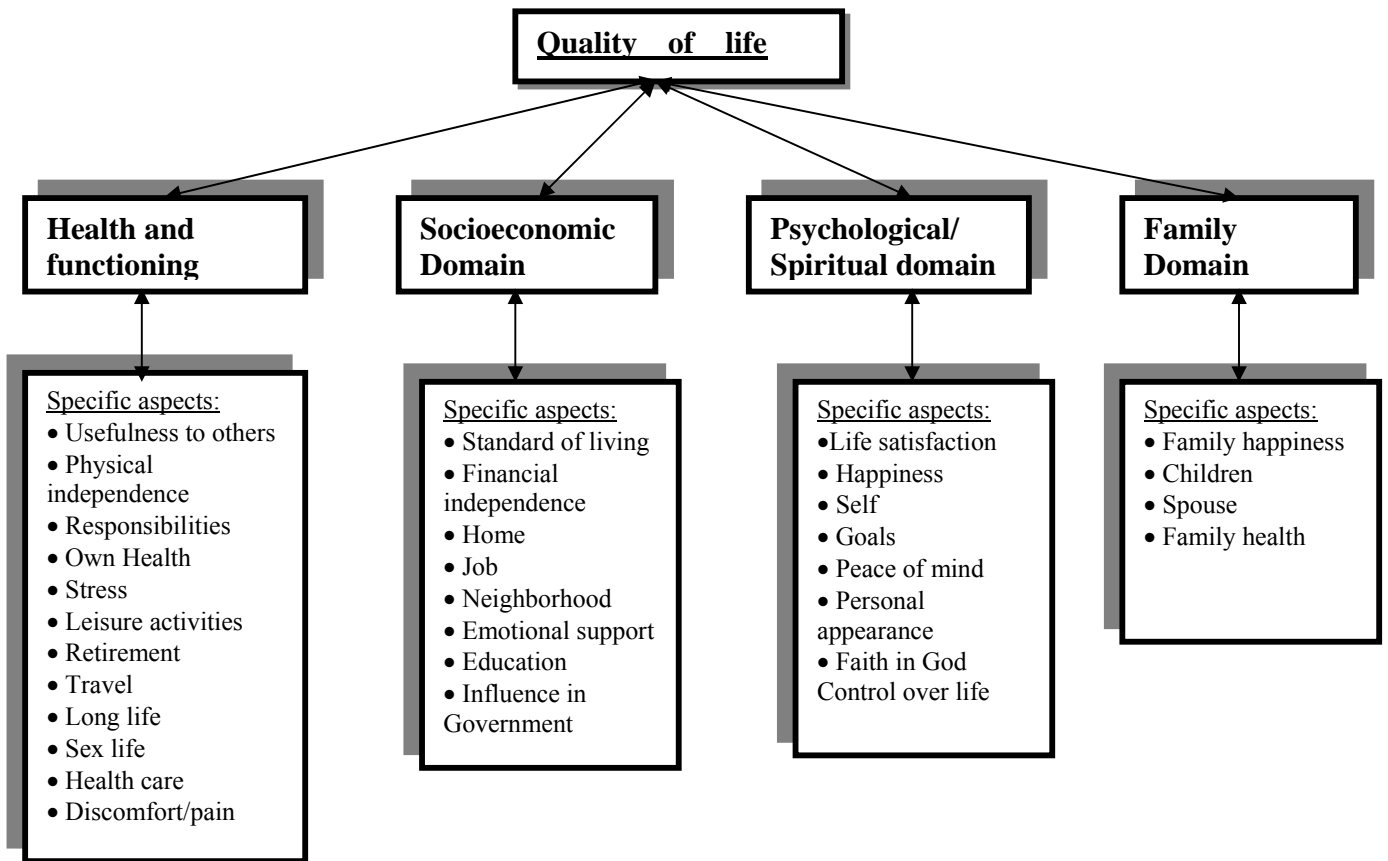
### **Theoretical Framework**

For the purpose of this study, the researcher has used two theoretical models, which play a complementary role in establishing the theoretical framework for this study. These two models are: Ferrans's Model, 1990b and Zhan's Model, 1992.

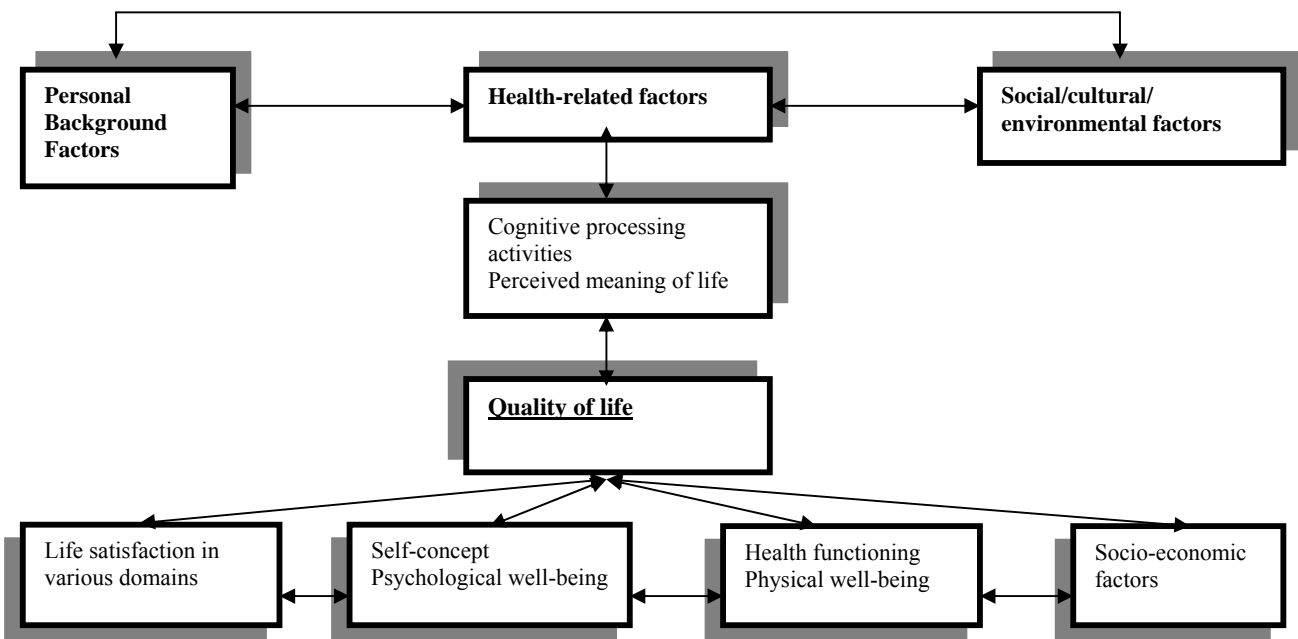
The conceptual model presented by Ferrans (1990b) described four major domains of QOL: health and functioning, socioeconomic, psychological/spiritual, and family. The conceptual model illustrates the hierarchical relationships between the global construct of QOL, the four major domains, and the specific aspects of the domain (figure 2). Zhan's model described QOL as a multidimensional concept that cannot be completely measured by either a subjective or an objective approach. Zahn identified dimensions of QOL as life satisfaction, self-concept, health and functioning, and socioeconomic factors. According to this model, QOL is also influenced by one's personal background, health, social situation, culture, environment, and age (figure 3). The perceived meaning of QOL comes from the interaction between the person and his or her environment (King & Hinds 1998).

It is clear from the two models that QOL is a holistic and multidimensional concept, which describes several dimensions like: physical, socioeconomic, psychological, and spiritual. Both models have connected the definition of QOL with the concept of the satisfaction. Moreover, the two models stress the importance of the interaction of the individual with his environment as a source of better QOL (satisfaction) or worse QOL (dissatisfaction). These assumptions are very crucial for this study especially for the refugees because the main stressors in their lives stem from "being a refugee and live in a very bad life conditions in the refugee camps".

Based on these two models and the WHO's definition of QOL, the researcher has chosen the (WHOQOL-BREF) instrument to assess and evaluate the QOL among the Palestinian refugees. WHO defined QOL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". This definition is completely consistent with the definitions of QOL in the Ferrans's and Zhan's Models, because it incorporates in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment.



**Figure (2): Ferran's Quality of Life Model**



**Figure (3): Zahn's Conceptual model of Quality of life.**

Source: (King & Hinds 1998).

### **Integration between this study and the different domains of the QOL in Ferrans's & Zhan's Models:**

According to Ferrans (1990b), the global construct of QOL has four major domains: Health and Functioning, Socioeconomic, Psychological and Spiritual, and Family. These domains might be influenced by 'being a refugee'.

The **camp environment**, where most refugees live, is an unpleasant environment. The crowdedness, as well as the lack of enough supplies and facilities affect the physical (e.g., more at risk, diseases), psychological (e.g., stress, fears, hopelessness), social (e.g., refugee status, roles), economic hardship, and mental health of the refugees. It is hypothesized that the impact of the camp environment on the QOL of the diabetic refugees is more intensified and worse than it would be on other individuals.

**The health and functioning** are affected by the refugee environment and its consequences. For example, the health care that the patient receives is inadequate, stress levels are higher than that of regular individuals, leisure activities may be absent, etc.

The diabetic refugee encounters additional problems in dealing with a chronic disease that affects every aspect of his life. The refugee patient is unable to carry out the required management of consistency in meals and medications. The refugee may not have enough resources or motivation and willingness to fulfill management and control objectives. The status of "refugee" itself has become a chronic condition that impacts his/her daily life. Diabetes may be seen just as another stress or problem, along with the many chronic problems that the refugee encounters. However, being a refugee with diabetes may add more negative impact to life situations (Al-Halabi, 1996).

**Socioeconomic factors:** In addition to disease process that the refugee is going through, he is deprived of certain social and economic benefits. For example, limitations in job, educational and financial independence may create special hardships. The socioeconomic status is mostly affected by the lack of resources and income. Beside inadequate basic needs resources, the refugees lack their leisure and recreational facilities. But as diabetics, they also lack resources for the management of a chronic disease. This results in a deterioration of their condition, leading to complications and additional stress and expenses.

**Family and the spiritual factors:** Diabetes affects individuals and their family life. Family life interferes with the physical, psychological, and social management of diabetes in different ways. Being a refugee is a situation in which the individual faces several kinds of problems (socioeconomic, psychological, cultural, and environmental) and hinders the QOL of diabetic refugees. Being a refugee with diabetes in a developing country and under occupation is a complicated situation for the individual and his family.

According to Al-Halabi (1996), the family is a very important unit for diabetics, for refugees and more importantly for refugees with diabetes, since family (spouse, children) is part of the immediate environment (home) where these persons live. They share many aspects of life and they are usually affected by the persons with diabetes. As part of the special value of this "only" immediate support system, the refugee with diabetes may not accept a special diet which "isolates" them from the rest of the family, because this is an important social life event for refugees. Insisting on being "a part of" rather than "apart" from this social family life is important where this reflects the selflessness and duty that refugees with diabetes would prefer to fulfill. It is part of the personal and cultural characteristics of the Arab or Muslim people. This reflects the psychological and spiritual dimension of QOL. But for refugees it is even more evident since the family "unit" is stronger and they all face the one "fate" at the end. Their faith in God gets stronger with every new problem they encounter. The belief system is very influential in almost every dimension of life; therefore, this would shape people's way of life and interpretation of events.

**Self-concept & Psychological Factors:** Remaining a refugee after 57 years of the initial relocation is a tragic experience for a Palestinian. Besides being displaced and uprooted for a long time, most refugees have moved more than once. Loss of Palestinian identity and lack of security along with the feelings of injustice that Palestinians have toward their situation and their separation from their homeland and relatives, have lead to decreased self-esteem and increased fears of more unknown problems. The continuous dependence on the relief work of the United Nations Agencies has created psychosocial and economic uneasiness for the refugees. These feelings are intensified by the fact that they have a homeland, rich in a variety of resources, which is being occupied by an enemy who destroyed most of their properties and "imported" foreign settlers to use and enjoy what they had once experienced. All these and other angry feelings influence the life of refugee persons.

**Conclusion:**

Diabetes, quality of life and refugees were connected and integrated in the framework used for the review of literature. The emerging framework was derived from a review of literature related to the experience of patients with chronic diseases (diabetes). It is clear from the above theoretical models, that in order to understand the experiences of the diabetic refugees more fully, it is important to have knowledge of their disease management styles, their level of perceived QOL, their satisfaction with specific domains of living, and how those domains contribute to their global QOL experience and to their management of diabetes.



## **Chapter 5**

### **Literature Review**

Because this study is the first one to investigate diabetes mellitus and its impact on the quality of life of the diabetic refugees in Gaza strip, this chapter reviews and analyses extensively the available literature on diabetes mellitus including, historical background, definition, classification, diagnosis and complications according to the international standards and the Palestinian guidelines. It also highlights the diabetes mellitus and its management in developing countries particularly in the Middle East. The concept of refugees with diabetes has been also discussed. Finally, the quality of life construct, quality of life and DM, and the impact of refugee status on QOL have been presented.

#### **5.1 Overview of diabetes mellitus**

##### **5.1.1 Historical background**

Diabetes mellitus is a disease that was recognized in antiquity (Ekoe, 2001). The term ‘diabetes’, which is from the Ionian Greek meaning to ‘pass through’, was first used by Aretaeus of Cappadocia in the second century AD as a generic description of conditions causing increased urine output (Papasperos et al.1964). Two forms of diabetes could be distinguished in the Indian’s descriptions: one affected older, fatter people and the other thin people who did not survive long; this strongly remind us the present clinical description of Type 2 and Type 1 diabetes (Papasperos et al. 1964 & McFarlane et al. 1997). The term diabetes mellitus, an allusion to the honeyed taste of the urine, was first used in the late eighteenth century by John Rollo and others to distinguish it from other polyuric states in which the urine was tasteless. The nineteenth century is the key century that has greatly contributed to the understanding of diabetes. Claude Bernard made numerous discoveries in the field of metabolism and diabetes. Oskar Minkowski and Josef Von Mering noted that total pancreatectomy produced diabetes in dogs. The pancreatic islets were named after Paul Langerhans by Edouard Lafresse. Langerhans had suggested that pancreatic islets produced a glucose-lowering substance. This substance was named insulin by Jean de Meyer in 1909, almost a decade before insulin was discovered (Ekoe, 2001). Although diabetes mellitus has been recognized for many centuries and major advances have been

accomplished since the discovery of insulin, there was no clear or widely accepted definition of diabetes until the early 80s.

### **5.1.2 Definition, diagnosis and classification**

**1. Definition:** WHO Expert Committee on diabetes mellitus (1985) defined the diabetic state as a state of chronic hyperglycemia which may result from many environmental and genetic factors often acting jointly. Hyperglycemia is due to defects in insulin secretion, insulin action or both.

According to the Palestinian Guidelines for Diagnosis and Management of Diabetes Mellitus (2003) which was created by the Palestinian MOH (PMOH) and derived from the new recommendations of ADA and the WHO report (1999):

- Several pathogenic processes are involved in the development of diabetes. These range from autoimmune destruction of the  $\beta$ -cells of the pancreas with consequent insulin deficiency to abnormalities that result in resistance to insulin action. The basis of the abnormalities in carbohydrate, fat, and protein metabolism in diabetes is deficient action of insulin on target tissues. Deficient insulin action results from inadequate insulin secretion and/or diminished tissue responses to insulin at one or more points in the complex pathways of hormone action.
- Symptoms of marked hyperglycemia include polyuria, polydipsia, weight loss, sometimes with polyphagia, and blurred vision. Impairment of growth and susceptibility to certain infections may also accompany chronic hyperglycemia.
- Acute, life-threatening consequences of diabetes are hyperglycemia with ketoacidosis or the hyperglycemic hyperosmolar state.
- The presence of diabetes impairs several aspects of phagocyte function, phagocytosis and intracellular killing of microorganisms; hyperglycemia reduces oxidative killing capacity. Infection impairs glycemic control and is one of the commoner identified precipitating factors for diabetic ketoacidosis.
- The emotional and social impact of diabetes and the demands of therapy may cause significant psychosocial dysfunction in patients and their families.

### **2. Classification of diabetes mellitus:**

Research, management and prevention of both Type 1 and Type 2 diabetes depend on an appropriate and contemporary classification (Zimmet, 1999; Amos, 1997; WHO, 1995).

Furthermore, a hallmark in understanding the etiology of a disease, studying its natural history and investigating the contribution of genes is the ability to identify and differentiate the various forms. DM can be classified into several forms as shown in (table 5):

**Table (5): Classification of diabetes mellitus**

<b>Type 1 Diabetes:</b>	Characterized by beta cell destruction, usually leading to absolute insulin deficiency. It has two forms: Immune-mediated diabetes mellitus: Results from a cellular mediated autoimmune destruction of the beta cells of the pancreas. Idiopathic diabetes mellitus: Refers to forms of the disease that have no known etiologies.
<b>Type 2 Diabetes:</b>	Disease of insulin resistance that usually has relative (rather than absolute) insulin deficiency. Can range from predominant insulin resistance with relative insulin deficiency to predominant insulin deficiency with some insulin resistance.
<b>Impaired Glucose Homeostasis:</b>	<b>A metabolic stage intermediate between normal glucose homeostasis and diabetes</b> (In the absence of pregnancy, these are <i>not</i> clinical entities on their own but rather risk factor for future diabetes and cardiovascular disease): <b>Impaired Fasting Glucose (IFG):</b> Fasting plasma glucose higher than normal, and less than diagnostic. <b>Impaired Glucose Tolerance (IGT):</b> Plasma glucose higher than normal, and less than diagnostic, following administration of a glucose load of 75 grams.
<b>Gestational DM:</b>	Glucose intolerance in pregnancy (Diabetes mellitus with onset or first recognition in pregnancy)
<b>Other specific types:</b>	Diabetes caused by other identifiable etiologies <ul style="list-style-type: none"> <li>• Genetic defects of beta cell function</li> <li>• Genetic defects in insulin action</li> <li>• Diseases of the exocrine pancreas (e.g., cancer of the pancreas, cystic fibrosis, pancreatitis)</li> <li>• Endocrinopathies (e.g., Cushing’s disease)</li> <li>• Drug or chemical induced (e.g., steroids)</li> <li>• Infection (e.g., rubella, Coxsackie)</li> </ul>

Source: Palestinian Guidelines for Diagnosis and Management of Diabetes Mellitus, 2003.

### 3. Clinical characteristics of type 1 and type 2 diabetes:

Table (6) presents the different characteristics of type 1 and type 2 DM:

**Table (6): Clinical characteristics of type 1 and type 2 diabetes**

Characteristic	Likely Type 1 diabetes	Likely Type 2 diabetes
Age	< 30 years	> 30 years
Peak age	10-14 years	50-60 years
Urinary ketones	Moderate to large	None to low
Body weight (BMI)	Usually thin (< 25)	Usually over weight (>27)
Clinical onset	Usually sudden	Usually gradual
Treatment	Insulin essential	<ul style="list-style-type: none"> <li>• Lifestyle interventions+ oral agents often effective.</li> <li>• Insulin for secondary failure.</li> </ul>

Resource: Palestinian Guidelines for Diagnosis and Management of Diabetes Mellitus, 2003.

### 4. Diagnostic criteria for diabetes mellitus:

Three ways to diagnose diabetes are possible and each must be confirmed by repeat testing on a different day by any one of the following methods (Table 7).

1. Symptoms of diabetes plus random (casual) plasma glucose concentration  $\geq 200$  mg/dl (11.1 mmol/l).
2. FPG  $\geq 126$  mg /dl (7.0 mmol/l)
3. 2-hours PG  $\geq 200$  mg /dl (11.1 mmol/l) during an OGTT

**Table (7): Diagnostic criteria for diabetes mellitus**

Stage	FPG	Random PG	OGTT
<b>Diabetes</b>	<b>FPG <math>\geq 126</math> mg/dl</b>	$\geq 200$ mg /dl plus symptoms	<b>2h-PG <math>\geq 200</math> mg/dl</b>
<b>Impaired glucose homeostasis</b>	Impaired Fasting Glucose (IFG) = <b>FPG <math>\geq 110</math> mg/dl and less than 126 mg/dl</b>		Impaired Glucose tolerance (IGT) = <b>2h-PG <math>\geq 140</math> mg/dl and less than 200 mg/dl</b>
<b>Normal</b>	<b>FPG less than 110 mg/dl</b>		<b>2h-PG less than 140 mg/dl</b>

Resource: Palestinian Guidelines for Diagnosis and Management of Diabetes Mellitus, 2003.

**Conclusion:** The new WHO/ADA recommendations (which were adopted by the Palestinian's MOH) will be welcome as a basis on which to build. The classification should provide a more rational platform for phenotyping and choosing appropriate therapies for persons with diabetes.

Also, an appropriate and correct classification and phynotyping is essential to ensure correct interpretation of primary prevention studies (Zimmet, 1999).

### **5.1.3 Complications**

People with diabetes are at increased risk of cardiovascular, peripheral vascular and cerebrovascular disease. The natural progression of the disease to nephropathy and retinopathy led to renal failure and blindness. The consequences of cardiovascular disease and neuropathy resulted in early cardiovascular death, foot disease and amputation. Although it is now evident to reduce the incidence of complications, or, when they occur, retard their progression, their prevalence and incidence remain unacceptably high (Ekoe & Zimmet, 2001).

The long-term complications of diabetes include progressive development of disease of the capillaries of the kidney and retina, damage to the peripheral nerves and excessive atherosclerosis. The clinical manifestations of these complications therefore include nephropathy that may lead to renal failure, retinopathy with potential blindness, neuropathy with risk of foot ulcers, amputation, and features of autonomic dysfunction, including sexual dysfunction. In the Middle East, for example, the only population-based study of chronic complications of diabetes in the Middle East was a survey of diabetes conducted in the urban and rural population of Egypt during 1991-1994 (Herman et al.1998). The results of this study revealed that, retinopathy was more common in previously diagnosed than in previously non-diagnosed patients (42% vs. 16%). Neuropathy was also more common in the previously diagnosed persons (22% vs. 14%). Peripheral neuropathy seems to be quite common in diabetic patients in the Middle East; the prevalence ranging from 14% in newly diagnosed Egyptian patients to 46% in Libya (Herman, 1998; Nielsen,1998; Kadiki 1999). However the prevalence of foot ulcers was found to be rather low (Herman 1998; Nielsen 1998). Some authors attribute this to a lower incidence or a shorter survival of affected patients (King, 2001). Other studies showed that diabetic patients in Bahrain and insulin-treated patients in Sudan amongst whom 38% and 44% respectively had diastolic hypertension (Al-Mahroos et al., 2000; Ahmed et al., 1995).

In the U.S., blindness, kidney failure, amputations, and cardiovascular disease resulting from diabetes not only markedly reduce quality and length of life but also cost nearly \$100 billion annually (Fleming et al., 2001). The EURODIAB study in 31 centers in 16 countries in Europe followed 3,250 patients with type 1 diabetes beginning in the late 1980s. There was a 56%

incidence of new retinopathy over 7.5 years for those without retinopathy initially. Neuropathy developed over 7.5 years in 24.6% of the patients. Patients with diabetes have a 2.5- to 5-fold greater risk than those without diabetes of having an increased coronary artery calcification (CAC) scores (Bloomgarden, 2002).

According to Gregg et al. (2003) diabetes could lead not only for physical complications but also for cognitive disabilities: as older adults make up an increasingly larger portion of the diabetic population, the spectrum of diabetes complications will likely expand. In addition to the traditional vascular complications, diabetes has been associated with excess risk for cognitive and physical decline, falls, fractures, and depression. These complications, which are common and can profoundly affect quality of life, will challenge clinicians, health care systems, and public health organizations to identify effective ways of optimizing quality of life among older adults with diabetes.

#### **5.1.4 Prevention of diabetes**

The prevalence of Type 2 diabetes is rising all over the world, with an ageing population living an increasingly sedentary lifestyle, and consuming, in relation to their energy expenditure, foods too high in fat and refined carbohydrate (Zimmet, 1999; Amos, 1997). Many developing countries already have high Type 2 diabetes prevalence and diabetes complications; which typically form the greatest social and health care costs of diabetes. With increasing urbanization of lifestyle these rates become even higher than European populations (De Courten et al., 1997; Zimmet, 1992). Because of this scenario, there is an urgent need for strategies to prevent the emerging global epidemic of Type 2 diabetes (Ekoe, 2001).

According to WHO Study group (1992), prevention of diabetes can be considered at three different levels. *Primary prevention* covers activities aimed at preventing diabetes from occurring in susceptible populations or individuals. *Secondary prevention* is aimed at early diagnosis and effective control of diabetes in order to avoid or at least delay the progress of the disease, and *tertiary prevention* includes those measures undertaken to prevent complications and disability due to diabetes (Tuomilehto et al., 1992; De Courten et al., 1998).

Studies in a number of populations, including Europeans, Native Americans, Indian, Chinese and African-born Mauritians, Samoans, Nauruans, and Melanesian Papua New Guineans have shown

that individuals with IGT have a higher risk of progression to Type 2 diabetes (between 2- and 7-fold higher) than persons with normal glucose tolerance (Tuomilehto et al., 1992; De Courten & Bennett et al., 1998). Therefore persons with IGT have formed the target group for interventions aimed at preventing Type 2 diabetes in several studies.

These preventive measures are of two main types- behavioral interventions based on changing diet and increasing physical activities, and/or therapeutic interventions using pharmaceutical agents to try and improve glucose tolerance and insulin sensitivity (Tuomilehto et al., 1992; De Courten et al., 1998).

**1. Behavioral interventions:** A number of short-term studies have suggested that in the longer term it may be possible to reduce the incidence of Type 2 diabetes. A study from the USA (Long et al., 1994) showed that weight reduction in morbidly obese subjects who underwent gastric bypass was associated with a reduced risk of developing diabetes relative to the control group who did not undergo surgery for non-medical reasons. The Swedish Malmo Study was the first to show that it was feasible to carry out a diet and exercise program for 5 years in men with IGT and reduce the incidence of Type 2 diabetes by 50% compared with the non-randomized control group (Eriksson & Lindgärde, 1991). In a high-risk Indian community in Tanzania, in which the benefits of exercise and a healthy diet were promoted, the 6-year incidence of Type 2 diabetes in men and women with IGT with a seemingly low 2.2% (Ramaiya, 1992). One of the best evidences yet that Type 2 diabetes can be prevented in people with IGT comes from a randomized intervention study reported from DaQing, China (Pan et al., 1997). Over six years there were significant and similar reductions in the incidence of diabetes in subjects with IGT who were randomized to diet, exercise or combined diet-exercise treatment groups. Recently, Eriksson et al. (1999) have reported on the study design and one-year interim report on the feasibility of a major Finish initiative: the Diabetes Prevention Study (DPS). The aim of the study was to assess the efficacy of an intensive diet-exercise program in preventing or delaying Type 2 diabetes in subjects with IGT. A total of 523 overweight IGT subjects have been randomized to a control or intervention group. The interim results show the efficacy and feasibility of the intervention program. Both weight and plasma glucose was significantly lower in the intervention group.

The Diabetes Prevention Program Research Group (DPP) (2002) in USA provided a detailed description of the highly successful lifestyle intervention administered to 1,079 participants, which included 45% racial and ethnic minorities and resulted in a 58% reduction in the incidence

rate of diabetes. The two major goals of the DPP lifestyle intervention were a minimum of 7% weight loss/weight maintenance and a minimum of 150 minutes of physical activity similar in intensity to brisk walking. To achieve these goals, the intervention was designed to be intensive and included features such as individual case management, frequent contact over the entire trial, a structured 16-session initial core curriculum and more individualized maintenance programming. These strategies proved to be very successful, as the lifestyle intervention resulted in a 58% reduction in the incidence rate of diabetes.

In the Finnish Diabetes Prevention Study, 522 subjects with IGT were randomized to either the intervention or control group. The intervention group was able to lose weight, increase physical activity, reduce the intake of total and saturated fats, and increase fiber intake more than the control group. These lifestyle changes resulted in a 58% reduction of diabetes risk. More interestingly, none in either group developed diabetes if they achieved four or five of the key targets of intervention (Long et al., 1994). As a conclusion, Type 2 diabetes can be prevented by changes in the lifestyles of high-risk subjects.

**2. Pharmacological Interventions:** These interventions are aimed at improving glucose tolerance and insulin sensitivity among IGT individuals and who are at high risk of progressing to Type 2 diabetes. A study conducted by Sartor et al. (1980), which showed that diet alone, or diet and tolbutamide, significantly reduced the incidence of Type 2 diabetes in males with IGT. The National Institutes of Health, USA, have now funded a major multicenter IGT intervention to examine the potential for Type 2 diabetes prevention (The Diabetes Prevention Program, 1999). In his study: “The Cost-Effectiveness of Preventing Diabetes”, Teutsch (2003) stated, “Quite clearly, the lifestyle intervention is more cost-effective than the metformin intervention, and the long-term benefits should be greater than those found within the trial. For those unwilling or unable to make the requisite lifestyle changes, the metformin intervention is a viable alternative”. According to Uusitupa (2002), it is important to notice that changing lifestyle is our primary target in the prevention of type 2 diabetes, since it is unrealistic to believe that any single drug we have today could become, in the large-scale, the first line means for the prevention of type 2 diabetes. This is also according to evidence-based medicine and nutrition; in well-controlled clinical trials, lifestyle changes have been shown more effective than drugs in the prevention of type 2 diabetes in high-risk groups.



As a summary, the WHO strongly recommends strategies for the prevention of type 2 diabetes, knowing the epidemics of the disease and its strong association with that of obesity. Several intervention studies, in China ("Da-Qing Study"), in Europe ("Malmö study", "Finnish Diabetes Prevention Study") and in the United States ("Diabetes Prevention Program"), showed that lifestyle change are able to reduce by around 50% the incidence of type 2 diabetes in at risk individuals. Various pharmacological approaches have also proven their efficacy in preventing type 2 diabetes, but in most cases with less impressive reductions, between 25% and 35% (Scheen, 2003).

**Conclusion:** These results from lifestyle intervention trials not only emphasize the importance of lifestyle in the prevention of type 2 diabetes, but they also strengthen the crucial importance of overweight and physical inactivity in the pathogenesis of this disease. Furthermore, they convincingly show that even moderate change in lifestyle matters. What is also of importance is the fact that changes in lifestyle can reduce the level of cardiovascular risk factors (Long et al. 1994).

### **5.1.5 Management of diabetes**

This part presents a variety of studies which emphasized different aspects of diabetes care including self-management training, family interventions, education programs, and effectiveness of coordination among the different levels involved in the diabetes care.

WHO study group on diabetes (1985) identified four objectives for the management of diabetes: to preserve the life of diabetic patient and relieve the symptoms of the disease; to enable the patient to have as normal a social life as possible; to establish and maintain good metabolic control; and to avoid the complications of diabetes.

Renders et al. (2001) reviewed the effectiveness of interventions targeted at health care professionals and/or the structure of care in order to improve the management of diabetes in primary care, outpatient, and community settings. The results of this study showed that multifaceted professional interventions and organizational interventions that facilitate structured and regular review of patients were effective in improving the process of care. The addition of

patient education to these interventions and the enhancement of the role of nurses in diabetes care led to improvements in patient outcomes and the process of care.

In a study to determine the relationship between the characteristics of families involved in disease management and the self-care practices of Hispanic and European-American (EA) patients with type 2 diabetes, a total of 74 Hispanic patients and 113 EA patients with type 2 diabetes recruited from managed care settings were assessed on three domains of family life (structure/organization, family world view, and family emotion management) and five areas of disease management (biological, general health and function status, emotional tone, quality of life, and behavioral). The results revealed that, for EA patients, scores for Family Coherence were negatively associated with HbA1c level and depression, and poor scores for Conflict Resolution were linked with high depression; for Hispanic patients, high scores for Organized Cohesiveness were associated with good diet and exercise, and high scores for Family Sex-Role Traditionalism were related to high quality of life. As a conclusion, characteristics of the family setting in which disease management takes place are significantly linked to patient self-care behavior, and these linkages vary by patient ethnicity. A family's multiple independent dimensions provide multiple targets for intervention, and differences in family norms, structures, and emotion management should be considered to ensure that interventions are compatible with the setting of disease management (Fisher et al., 2000).

Another study (Norris et al., 2001) conducted to systematically review the effectiveness of self-management training in type 2 diabetes. A total of 72 studies described in 84 articles were identified for this review. Positive effects of self-management training on knowledge, frequency and accuracy of self-monitoring of blood glucose, self-reported dietary habits, and glycemic control were demonstrated in studies with short follow-up (<6 months). With longer follow-up, interventions that used regular reinforcement throughout follow-up were sometimes effective in improving glycemic control. Educational interventions that involved patient collaboration may be more effective than didactic interventions in improving glycemic control, weight, and lipid profiles. It is concluded that, evidence supports the effectiveness of self-management training in type 2 diabetes, particularly in the short term.

Philis-Tsimikas et al. (2004) conducted a study to improve clinical diabetes care, patient knowledge, and treatment satisfaction and to reduce health-adverse culture-based beliefs in underserved and underinsured populations with diabetes in San Diego County, California. A total of 153 high-risk patients with diabetes recruited from six community clinic sites in San Diego

County, California were enrolled in a nurse case management (NCM) and peer education/empowerment group. This novel, culturally appropriate, community-based, nurse case management/peer education diabetes care model leads to significant improvement in clinical diabetes care, self-awareness, and understanding of diabetes in underinsured populations. In order to assess the effectiveness of a new dietary education (NDE) program in reducing plasma glucose (PG) levels in Japanese male workers at high risk for type 2 diabetes through a randomized controlled trial, 173 high-risk men were randomly assigned to either the NDE or the control (conventional dietary education) group. The results of the study showed that, the NDE group had a significantly lower total energy intake at dinner and daily than the control group. The NDE group had a decreased 2-h PG after 1 year, whereas that value was increased in the control group. As a conclusion for this study, the NDE was shown to reduce glucose levels in high-risk subjects for type 2 diabetes as an evidence of the importance of dietary change in preventing the occurrence of diabetes or at least delaying the complications (Watanabe et al. 2003).

A study (Gruesser et al., 1993) performed in Germany to evaluate the practicability and efficacy of a structured treatment and teaching program for non-insulin-treated type II diabetic patients in routine primary health care. All physicians (n = 139) and their office staffs in Hamburg, who had participated in a special training course from 1 April 1991 to 31 December 1991 were contacted for a standardized interview. The study revealed that the program was well received by the physicians, and the data collected on 179 patients demonstrated the efficacy of the program at the treatment level: reduction of body weight and HbA1c levels was substantial. The individual prescribed volume of oral anti-diabetic agents was approximately 50% lower after patient attendance of the program. It is concluded from the study that, subsequent to the introduction of nationwide remuneration of outpatient education for type II diabetic patients by office-based physicians, a relevant improvement was observed in the quality of care, comparable with the effects of the program in a previous prospective controlled trial.

Finally, The Health Care Delivery System work group for the November 1999 conference on Behavioral Science Research in Diabetes in USA evaluated the status of research on quality of care, patient-provider interactions, and health care systems' innovations related to improved diabetes outcomes. They conclude that, the quality of care provided to the vast majority of diabetic patients is problematic; this is principally not the fault of either individual patients or

health care professionals. Rather, it is a system issue emanating from the acute illness model of care, which still predominates. This article recommended the establishment of proactive population-based chronic care management programs (models) to deal with the escalating problem of diabetes. Key characteristics of these programs are: first, these programs are systems based and focused on entire defined population groups. They do not rely on individual providers or educators to remember to do things correctly, but create an environment that supports and reinforces self-management and guidelines for concordant care, rather than creating obstacles to these objectives. Second, these programs are proactive and provide prompts, reminders, and cues for both patients and health care professionals. Third, successful programs also provide consistent follow-up support so that goals, or even patients, are not lost. Fourth, successful chronic care programs should involve the patient as an active team member and stress patient-centered collaborative goal setting. Fifth, they establish a set of guidelines or care responsibilities for the entire team and distribute these responsibilities across team members, rather than relying on primary care physicians to provide the vast majority of services. Sixth, successful programs change the way in which chronic care is conducted. Interactive contacts (e.g., visits and calls) are planned and designed to focus on needed support, outcomes, and outcomes-related processes. Finally, to be successful with all patients, it is necessary to have a clinical information system that supports and integrates the above-listed activities. This system involves a diabetes registry, which is usually computerized and used to inform and prompt care (Glasgow et al., 2001).

## **5.2 Diabetes mellitus in developing countries and the Middle East**

**Developing countries:** A profusion of studies worldwide have confirmed that an epidemic of type 2 diabetes, as part of the "globalization" process, is occurring across the world affecting particularly developing countries. The results of numerous epidemiological studies suggest that the prevalence of diabetes will dramatically increase in the next quarter of this century both in developed and developing countries (Ekoe et al., 2001). The World Health Organization (King et al., 2001) suggests an increase worldwide in the prevalence of diabetes in adults of 35% and an increase in the number of people with diabetes of 122%. The developing countries will face an increase of 48% in the prevalence of, and an increase of 170% in the number of people with, diabetes compared to an increase in the prevalence of diabetes of 27% in developed countries, with an increase of 42% in the number of people with diabetes.

**Middle East:** Dramatic changes are taking place in the epidemiological pattern of disease in most countries of the Middle East. Declining incidence of infections and under-nutrition is associated with a concomitant increase in morbidity and mortality from non-communicable diseases. Socio-economic development, urbanization and associated lifestyle changes are undoubtedly the underlying causative factors for this accelerated epidemiological transition, since several countries of the region have experienced rapid socio-economic changes in the last few decades (King & Roglic et al., 2001). All countries of the WHO Eastern Mediterranean (Middle East) region have experienced an increasing availability of calories for consumption during the last 20 years (WHO, 1989). The few available studies indicate that about one-third of the adults in countries of the region are obese (WHO, 1997), and the prevalence of obesity in children is amongst the highest in the world (de Onis & Blossner, 2000).

In the last few years, important epidemiological surveys have been reported from Bahrain, Egypt, Jordan, Oman, Pakistan and Saudi Arabia. They employed comparable methodology and diagnostic criteria, and they deliver a consistent and disturbing message: diabetes in those populations is now at least twice as prevalent as in Europe and North America (King & Roglic et al., 2001). In Oman 10% of adults found to have diabetes, with a similar proportion suffering from IGT (Asfour, 1995). Moreover, the high frequency of diabetes was not confined to the urban areas, since all parts of the country showed the same basic pattern in this national study. In Pakistan, 16% of men and 12% of women aged 25 years and above were found to have diabetes, and the prevalence of diabetes and IGT combined was 25% in both sexes (Shera et al., 1999). The latest survey of glucose intolerance among Saudi populations in rural and urban communities documents an ever-greater prevalence of diabetes in subjects 15 or more years old. The age-adjusted prevalence of diabetes was 12% in urban men and 14% in urban women (Al-Nuaim, 1997). In a survey of cardiovascular disease prevalence in men aged 40-59 years and women aged 50-59 years in Bahrain, the age and sex standardized prevalence of diabetes was 25% in Jaafari Arabs, 48% in Sunni Arabs, 23% in Iranians and 31% in the unclassified subjects (Al-Mahroos, 1998). The survey conducted in Egypt, under the auspices of the US Centers for Disease Control and Prevention (Herman et al., 1995) demonstrated a wide range in prevalence, from 5% in adults in rural areas, to 20% in the upper socio-economic urban residents. This illustrates the importance of environmental factors, as well as the potential for primary prevention. The authors estimate the prevalence of diabetes in the total Egyptian population over

the age of 20 years to be 10%. A study of four semi-urban in Jordan showed prevalence of 13.4% for diabetes and 9.8% for IGT (Ajlooni et al., 1998).

Based on the available studies, a recent WHO report estimates the total numbers of persons with diabetes in the Middle East to be 22 million in the year 2000. If current trends in population growth and urbanization continue, there will be 53 million adult persons with diabetes living in countries of the Middle East in the year 2025, the majority of them being in the middle age range. Between 1995 and 2025 the prevalence will have increased by 30%, from 6.3 to 8.2%. There will be a considerable excess of diabetes in urban areas, and similar numbers of males and females with diabetes (King et al., 1998).

In high prevalence populations, diabetes also tends to develop at a relatively early age. The age specific data from Oman indicate that approximately 9% of females aged 20-29 years have diabetes or IGT (Asfour, 1995). Comparable figures were obtained in Pakistan (Shera et al., 1999). This indicates the importance of glucose intolerance as a complication of pregnancy in such susceptible populations. In Oman and Pakistan alike, prevalence of diabetes rose to 30% in subjects in the older age groups. Thus, we can now assume that one-third of all persons in these countries may expect to develop diabetes, unless they die prematurely of something else (Ekoe et al., 2001). These alarming figures fit convincingly with the hypothesis that populations in formerly harsh environmental conditions, such as living in the deserts which cover much of the Middle East, have developed an efficient metabolism in order to survive (Neel et al. 1962; Pugh et al., 1998). This former advantage (the so-called thrifty genotype) proves detrimental once a modern lifestyle, characterized by high-energy diet and low level of habitual physical activity, is adopted; hence the recent emergence of diabetes and associated disorders as a major threat to the health of the developing world (King & Roglic 2001).

**Conclusion:** Type 2 diabetes represents one of the most serious public health threats to the populations of the Middle East and the situation may be expected to worsen in the near future due to population growth, aging and rapid urbanization. Concreted measures aimed at both primary and secondary prevention are required at a regional level. Type 1 diabetes has generally been reported to be rarer than in European populations, but incidence may have been underestimated.

### **5.3 DM management in developing countries**

In many developing countries, health care services are inadequate and of poor quality. Objective data on the quality of health care systems are limited. Registers are mainly local, not always comparable, and cover only few aspects of the diseases recorded. This is a major obstacle to all efforts to improve the quality of health care. Although some data are available from few epidemiological studies on prevalence and incidence of diabetes, the picture is usually incomplete (Piwernetz et al., 1992). A key element of comprehensive health care for diabetics is health manpower planning. In the developing countries, however, restricted resources and scarcity of trained personnel, and the priority of other health-related demands on their time, means that much of the responsibility of diabetes care falls upon manpower resources within the community, e.g., village schoolteachers, health volunteers, etc., which affect the quality of care provided for the diabetics. The supply of the basic therapeutic requirements for diabetes management is inadequate or non-existent in some developing countries (WHO, 1985). In some developing countries, mortality from acute complications appears to be unacceptably high, owing to a lack of the basic requirements for treatment (e.g. insulin). Similarly, inadequate facilities for secondary and tertiary prevention in both Type 1 and Type 2 diabetes will result in the development of early complications, which will progress to early functional impairment and disability in a moderate proportion of patients. The majority of children with Type 1 diabetes in developing countries die within 5 years of diagnosis, whereas in industrialized countries, the median life expectancy of a type 1 diabetes patient today is approximately 70-80% of that in the general population (Songer et al., 1992). A very good article issued by Zgibor and Thomas (2001) tried to explore perceived and real barriers to diabetes care that may prevent implementation of evidence-based practices in developing countries and result in patients not seeking care, non-adherence to treatment recommendations, and poorer health outcomes. Those barriers include patient-, provider-, and health care system-based issues. For example, patients with lower socioeconomic status, lower levels of income, and who live in the most impoverished areas reported more problems obtaining medical care, were less likely to have health insurance and to see a physician in the previous year, and were less likely to report good health. Those with lower levels of education were less likely to have heard of HbA<sub>1c</sub> testing and were less likely to have received diabetes education or to report good health. Barriers related to health care system associated with poorer levels of care include the lack of health insurance, differing practice patterns between generalist and specialist physicians and poor distribution of health and care institution; e.g., residents of the rural

community face many difficulties to obtain the desired health care services because most of health care settings are located in the urban areas. Another barrier to provide a quality diabetes care in developing countries is the lack of diabetes specialists. It is estimated that more than 90% of physician visits of diabetic patients are to primary care providers, which leads to lower use of preventive services and poorer glycemic control.

All of these above-mentioned barriers are found in Gaza strip especially in the refugee camps where the lack of supplies and the lack of health professionals are the dominant signs in providing diabetes care.

The following section provides some evidence-based studies in Africa, Asia and Latin America, which show the daunting picture of the diabetes management in the developing countries.

**Congo:** The management of diabetes in Congo and, in particular, its complications are suffering because of some cultural influences but mainly economic ones. In fact, incidence of disease complications is closely linked to the financial status of patients and facilities. For the large majority of Congo population, education on diabetes is not available, and due to the failure of the national health system, access to treatment is impossible. Furthermore, because most diabetic people in Congo go untreated, the mortality rate for the disease is high (Mottini et al., 2003).

**Algeria:** The results of initiating an educational training program for general practitioners in Oran, Algeria, about diabetic foot ulcer (DFU) management were disappointing. In spite of implementing educational program for general practitioners (GPs), no improvement in the DFU management was noted as emphasized by absence of any significant change in amputation rate before (1st period) and after initiating the program (2nd period). These disappointing results can be explained by several factors: weakness of the educational program, lack of motivation from GPs, absence of a structured multidisciplinary prevention approach. The main problem, common to developing countries, remains the insufficiency of financial resources. Moreover, civil disturbances can make the problem more difficult to manage, as in Algeria since 1991 (Benotmane et al., 2004).

**Latin America:** A study conducted in 10 Latin American countries to implement an educational program and to evaluate its effect on the clinical, biochemical, and therapeutic aspects as well as the economic cost of diabetes. This study confirmed a severe deficiency of educational resources



in Latin America, in addition to a lack of participation from the diabetics in the treatment of the disease (Gagliardino et al., 2001).

**Thailand:** Other study (Aekplakorn et al., 2003) was done in Thailand showed that many patients (31%) turn to other traditional treatments such as Chinese medicines or herbs. This implies the desperate need for well-planned educational programs.

**Indonesia:** Predictions indicate a potentially explosive increase in the prevalence of diabetes in Indonesia with varying rates between those living in urban and rural areas due to differences in ethnics, race, culture and lifestyle. The level of obesity among the general population has increased, due partly to increased calorie intake and due to changes in lifestyles. The new types of the diabetes are clinically more difficult to assess than the classical types 1 and 2, as they require relatively costly genetic and immunological studies (Sutanegara et al., 2000).

**Trinidad, Caribbean region:** A study by Ezenwaka & Offiah (2003) demonstrated that Type 2 diabetic patients in the Trinidad, Caribbean region were well informed about diabetes risk factors and benefits of healthy lifestyle. Given our recent reports on poor metabolic control, application of this theoretical knowledge in controlling their diabetes remains doubtful.

**Egypt:** In a study (Kamel et al., 1999) aimed to describe the level of knowledge of diabetic patients about the disease and reveal the relationship between knowledge and management-related behavior of diabetics in Alexandria, Egypt. It is found that a majority of diabetic patients (90.0%) had poor knowledge about the disease, 83.7% had poor knowledge about the complications associated with diabetes and 96.3% had poor awareness of how to control the disease. *This study is a contradictory for the previous study done in Trinidad, Caribbean region. In Egypt, there is poor knowledge, but in Trinidad, the diabetic patients are well informed but the application of this knowledge was doubtful.*

**Bahrain:** The current programs to manage and control diabetes in Bahrain are limited and ineffective. Training of physicians in the management of diabetes, public education, epidemiological surveys, and nutritional evaluation of local foods are among the most important measures needed to control diabetes in Bahrain. Although, diabetes mellitus 1 has a higher death rate than that of hypertension, physicians in Bahrain tend not to list diabetes mellitus as the main cause of death; thus there is underreporting of diabetes-related mortality. Bahrain does not have programs to detect or control diabetes. Health workers are not properly trained. The effectiveness of mass media to promote prevention of diabetes is low, because educational programs are poorly designed and unattractive (Musaiger, 1992).

**Nigeria:** According to this study (Famuyiwa, 1990), the problem of diabetes in Nigeria is more than the high prevalence of diabetes and the clinical pattern of the disease itself, it is the social, economic, and cultural circumstances within which the disease is managed, that give it its "tropical" distinctiveness. Factors of illiteracy, poverty, lack of adequate shelter or source of safe drinking water, poor environmental sanitation, cultural misconceptions about diseases, scarce health resources, non-availability of drugs or their prohibitive cost, the sale of fake drugs, and of course the ubiquitous traditional and faith healers with their 'miracle cures', all combine to create a milieu which is hostile to the optimal management of a chronic lifelong disease like diabetes mellitus. Another survey of twelve pharmacies in Nigeria (Famuyiwa et al., 1985) revealed that many of the oral hypoglycemic agents, insulin, syringes, needles and materials for urine testing are not stocked by most of them.

**Tanzanian:** In a study (Smide et al., 2002) conducted to compare self-care and perceived educational needs in adult Tanzanian and Swedish diabetic patients. The comparison indicated the Tanzanians were dissatisfied with the lack of drugs and wanted more diabetes education while the Swedes were more dissatisfied with their own self-care behavior. None of the Tanzanians monitored their own blood glucose, whereas half the patients in the Swedish group did so weekly or monthly.

#### **5.4 Diabetes mellitus and the refugee life**

No previous studies have been found in the literature addressing the effect of diabetes mellitus on the refugees' life. Only some indirect studies have been captured which discuss the relationship between the low socioeconomic status and poor health care, and the refugees. The researcher has tried in this subsection to connect between the refugee life and the difficult health conditions of the diabetic refugees particularly the Palestinians.

Refugees with diabetes, regardless of their location, suffer from lack of access to and quality of care, social support, and community resources. This influence diabetes-related knowledge, communication with providers, ability to adhere to recommended medication, exercise, and dietary regimens, and treatment choices. Correspondingly, these disparities in health have a profound impact on the morbidity and mortality associated with diabetes.

The relationship between lower socioeconomic status and poor health care outcomes has been postulated by Brown et al. (2004) that includes poorer access to care, poorer quality of care, and

worse self-care behaviors (such as diet and exercise behaviors), which may contribute to other diseases and further decreased function. According to Brown et al. (2004), there is considerable evidence that the social status of persons with diabetes and the characteristics of their communities or neighborhoods (like the camps environment) may determine their risk of mortality and diabetes-related complications such as cardiovascular disease, retinopathy, end-stage renal disease, and amputation, as well as their quality of life. Lower individual socioeconomic position, like refugees status, has been associated with poorer physical or emotional health (Ware et al., 1996), poorer glycemic control (Caddick et al., 1994) and increased risk of microvascular disease (Connolly & Kesson, 1996; Chaturvedi et al., 1996).

Evidence is strong for a relation between social isolation and greater morbidity and mortality (Berkman & Syme, 1979; Balfour & Kaplan, 2002). Poorer persons are at higher risk of social isolation and of having fewer supportive social ties (Oakley & Rajan, 1991; Turner & Marino, 1994) and among persons with diabetes, low SEP may have a larger negative effect for people with lower levels of social support. Researchers in one small study found that under conditions of high stress, which tend to be more prevalent among people of lower socioeconomic position (like the refugees), persons with less social support had higher hemoglobin A<sub>1c</sub> levels than persons with more social support (Griffith, 1990).

Control of blood glucose levels has been closely linked to stress in studies of type 1 and type 2 diabetes (Lloyd et al., 1999; Kramer et al., 2000; Inui et al., 1998; Surwit et al., 2002). A study has shown that recent severe stressors are associated with poorer glycemic control (Lloyd et al., 1999). It has been suggested that stress may impair glucose control through two different pathways: behaviors, such as a reduction in medication adherence, and neurohumoral pathways, notably the counter-regulatory hormones (Barglow, 1984). Allostatic load, the cumulative biologic burden associated with the body's adaptation to chronic stress, may be a particularly important mechanism through which low socioeconomic position affects health outcomes for persons with diabetes (Seeman et al., 2001). **In contrary**, a study (Kulenovic et al., 1996) conducted to investigate the impact of almost 3 years of war on glycemic control and blood pressure in Sarajevans with non-insulin-dependent diabetes mellitus (NIDDM) showed that the percentage of patients with NIDDM with acceptable blood glucose values increased from 15 to 35%. The values of HbA<sub>1c</sub> improved significantly but no differences in the total serum cholesterol or in the triglyceride levels were found. Twenty-five of the participants were

hypertensive before the war compared with only 14 in 1994-1995. The number of patients controlled without any anti-diabetic medication increased from 3 to 13. The reduction in anti-diabetic drugs and blood pressure probably occurred as a result of the significant weight loss. It can be concluded that glycemic control and the level of hypertension improved in patients with NIDDM in Sarajevo during the war.

As a summary, the previous studies have demonstrated that diabetic people with low socioeconomic status and poor health access (like the refugees) are at risk of higher mortality rate and diabetes-related complications. Stress and the social isolation which most of the refugees suffer from exacerbate their health situation especially diabetes.

## **5.5 Overview of diabetes research**

Improvement of the health status of the diabetics depends on both effective health care and related research (WHO, 1985).

Some of the important developments in diabetes have emerged through epidemiology. The rising prevalence and incidence of type 2 diabetes in many populations has stimulated research on the genetic, environmental, behavioral, socioeconomic, and cultural factors contributing to the epidemic of diabetes. The recent advances that have been accomplished so far in different epidemiological studies have increased our knowledge about different types of diabetes worldwide. But, it is still worthwhile to continue to perform large scale population surveys in communities where that information is lacking (Ekoe et al., 2001).

Why we need diabetes field surveys?: Because of the existence of pools of both clinically mild untreated cases and undiagnosed cases, irrespective of population, studies of Type 2 diabetes and its complications that rely on routine data sources and clinic attenders will be subject to considerable bias. For this reason, population-based surveys are necessary to probably define the spectrum of Type 2 diabetes (WHO, 1985; Dowse & Zimmet, 1994).

The need for field surveys is particularly important in developing countries where Type 2 diabetes is becoming increasingly common, and 'routine' sources of information, such as hospitalization and mortality data, are either not available or at best incomplete (Zimmet et al., 1993; King & Rewers, 1993; Dowse & Zimmet, 1994). Indeed, surveys performed in the developing world over the years since standardized criteria for diagnosis of diabetes have highlighted the emergence of virtual epidemics of Type 2 diabetes as a significant global public health problem (WHO, 1985; King & Rewers, 1993; McCarty & Zimmet 1994).

A review article (Winget al., 2001), which grew out of a National Institute of Diabetes and Digestive and Kidney Diseases conference on behavioral science research in diabetes, identifies four key topics related to obesity and physical activity among diabetic patients that should be given high priority in future research efforts: 1) environmental factors related to obesity, eating, and physical activity; 2) adoption and maintenance of healthful eating, physical activity, and weight; 3) etiology of eating and physical activity; and 4) multiple behavior changes.

A literature review study (Satterfield et al., 2003) of community-based interventions intended to prevent or delay type 2 diabetes offered important reflections about the process of engaging communities and sharing decision making in participatory research approaches, as well as insights about the expectations and limitations of community-based diabetes prevention research.

Another problem emerges in the diabetes research is the gap between theory and practice. Despite the promising advances in the diabetes research, it is well documented that there is a large gap between what is known about diabetes care and what is commonly practiced. To accelerate the translation of research to practice, Glasgow (2003) suggested especially needed methods that will 1) enhance and measure the reach of interventions, especially toward poor, underserved, and minority populations; 2) develop programs that can be widely adopted by diverse settings; 3) produce replicable effects and enhance quality of life, in addition to short-term behavioral or biological outcomes; 4) be consistently implemented by different staff members having moderate levels of training; and 5) produce maintenance at both individual and setting levels and at reasonable cost.

Hiss in his article (2001) addressed some barriers to widespread adoption of new science into clinical care, these include: 1) *The asymptomatic nature of diabetes*. During the pre-complication phase and the early phase of most complications, the type 2 diabetic patients are asymptomatic. As a consequence, the driving forces that cause most people to seek medical care -unpleasant symptoms and fear of a serious illness- are not present. Valuable time, during which intensive and continuous preventive care could forestall or prevent complications, is lost. 2) *Attitudes/beliefs/misconceptions*. Although diabetes has been recognized for years as a life-threatening and therefore serious illness, type 2 diabetes has traditionally been lightly regarded by both provider and patient. 3) *Acute/episodic health care system*. The current health care delivery systems in many developed and developing countries are primarily designed to react to acute and episodic events. However, chronic illnesses are not well served by these current systems, as they

require a long-term plan that is proactively implemented in a before-the-fact (preventive) manner.

3) *Confounding influence of obesity*. The misinterpretation on the part of health care providers of the etiology of obesity in the diabetic patient places a wall between provider and patient. Providers interpret obesity as evidence of patient noncompliance, which adversely affects the provider's care plan. For their part, patients avoid encounters with their health care providers about their diabetes because the experience is often demeaning and judgmental. 4) *Health economics*. In many developed and developing countries there is unevenness of access to medical care across the population, and there are millions of people without any insurance at all. Furthermore, the distribution of the medical institutions and health centers are uneven in the urban and rural areas. Hiss, at the end of his article, recommended three steps to overcome such barriers: first, identify the operative barriers and the specific settings to which they apply. Second, is to design a novel translational strategy that the recipients will welcome because it lessens one of their problems without increasing any of them. The third and final step is to implement a chronic disease model of care. Such a system could provide the previously identified essential services that people with diabetes will require for the rest of their lives, and it could provide appropriate payment for each of them.

In conclusion, many different types of research -basic research, clinical research, operational research, research in health economics, and population studies- need to be coordinated to optimize their effect upon the health of diabetics. This requires motivation, organization, appropriate resources at local, national, and international levels, and good communication between clinicians and research workers.

## **5.6 Quality of life**

### **5.6.1 Introduction**

„There is no profit in curing the body if in the process we destroy the soul." ---SAMUEL GOLTER, CITY OF HOPE MEDICAL CENTER, DAURTE, CA.

"Adding years to life" is an empty victory without "adding life to years." ----- (WHO, 1998).

Quality of life is an increasingly common theme in the health status and health promotion literature. That is improved quality of life is seen as a desired outcome of service provision. Quality of life assessments can also identify individuals in need of support or interventions, even

in the absence of diagnosable illness or other problems. From a broader health promotion or illness prevention perspective, quality of life may be seen as an indicator of health risk, either physical or mental, in the absence of present treatment or service need (Raphael et al., 1996).

The dramatic rise in average age of death in developed countries has brought the realization that longevity should be accompanied with improvements in health-related quality of life (HRQOL). Some researchers have raised the possibility that increasing life expectancy will result in an increase in the proportion of the population living in poor health, with the consequent increased burden on society and health care services (Manuel and Schultz, 2004). The World Health Organization (WHO) succinctly summarizes these concerns by stating that "adding years to life" is an empty victory without "adding life to years" (WHO, 1998). The Quality of Life Research Unit in the Department of Public Health Sciences, University of Toronto stated that: "The ultimate goal of quality of life study and its subsequent application to people's lives is to enable people to live quality lives -- lives that are both meaningful and enjoyed" (Renwick, 2002).

**Historical perspectives:** Although the use of the term quality of life has primarily been limited to outcomes associated with clinical research, the term has been around for a long time (King & Hinds, 1996). Historically, quality of life first appeared as a concept in Greek philosophy. Aristotle suggested that happiness was derived from virtuous activity of the soul and led to a good life (McKeon, 1947 In King, 1996). In contemporary times, members of the WHO (1947) implicitly introduced the concept of quality of life into health care when they defined health as "a state of physical, mental, and social well-being and not merely the absence of disease or infirmity". It was not until 1978, however, that the WHO explicitly stated that all individuals have a right to psychosocial care and an adequate quality of life in addition to physiologic care (King & Hinds, 1996). In 1975, QOL term was introduced as a key term in medical indexes, and its systematic study started in the early '80s mainly within oncology, since physicians were confronted with the problem that the cure could be too high a price to pay for the resulting increase in life expectation. More recently, QOL has emerged as an important attribute of clinical investigation and patient care, being devised to take into account anything beyond mortality and symptom levels. Its use reflects a growing appreciation of the importance of how patients feel and how satisfied they are with treatment, besides the traditional focus on disease outcomes (Berlim and Fleck, 2003).

**Defining QOL:** Quality of life assessment is complicated by the fact that there is no universally accepted definition for QOL. In the past, many researchers measured only one dimension, such as physical function, economic concern, or sexual function (Table 8). More recently, researchers have attempted to further define QOL (King & Hinds, 1996; Naess, (1987) In Raphael et al., 1996).

*For the purpose of this dissertation the researcher has adopted the* WHO’s definition of QOL which identifies it as a multidimensional concept and defines it as "individuals' perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns" (WHO, 1993). The definition includes six broad domains: physical health, psychological state, level of independence, social relationships, environmental features, and spiritual concerns. McDowell & Newell (1987) suggest that quality of life "relates both to the adequacy of material circumstances and to people's feelings about these circumstances". Coulter (1990) defines quality of life as "a sense of personal satisfaction with life that is more than just pleasure or happiness and yet something less than meaning or fulfillment". Raphael et al., (1996) defined quality of life as: the degree to which a person enjoys the important possibilities of his/her life.

<i>Approach</i>	<i>Focus</i>	<i>Definition</i>
Medical	Persons with diseases	QOL represents the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient. (Schipper et al., 1990)
Health-Related	Persons with illness or disabilities	QOL is recognized as a concept representing individual responses to the physical, mental, and social effects of illness on daily living which influence the extent to which personal satisfaction with life circumstances can be achieved. (Bowling, 1991)
Social diagnosis	Persons in communities	...the adjustment and life satisfaction of community members.(Green & Kreuter, 1991)
Centre for health promotion	All persons	The degree to which a person enjoys the important possibilities of his/her life. (Rootmann et al., 1992)

**Table (8): Various Definitions of QOL**



Though these definitions provide different views of quality of life, each emphasizes different aspects and approaches, for example: Schipper's (1990) approach to quality of life illustrates the medical view; it is closely linked to the effects of illness upon individuals. Bowling's (1991) approach illustrates a more health-related, rather than illness-related view of QOL. His attempt is made to focus upon health rather than illness and positive rather than negative aspects of behavioral functioning. This review is consistent with the WHO's definition of health as involving physical, mental, and social well being and not merely the absence of disease or infirmity. Another approach that assesses quality of life from the social view is Green and Kreuter's (1991) model. This model focuses upon behavioral change issues, which fall within the purview of traditional health workers: illness prevention, health status, life-style behaviors, and health education. Green and Kreuter's (1991) contribution to the quality of life discussion is to highlight the need to bring the consumer into the development, implementation, and evaluation of health services and promotion programs (Raphael et al., 1996).

**Measuring QOL:** Because the use of scientific methods to assess QOL is in its infancy and a gold standard for QOL assessment does not exist, caution in applying QOL measures to allocate health care resources is imperative (King & Hinds, 1996). QOL research has demonstrated differences between QOL assessments made by health care providers and patients. When discussing QOL, it is important to distinguish it from related, but different, concepts, including well-being, health status, life satisfaction, and hope. It is important also to evaluate the relationship of culture and QOL because QOL perceptions of an individual are culture bound, varying from society to society. Little work has been done to address cultural issues in QOL research and the impact of culture on perceptions of QOL (Fowlie et al., 1989; King et al., 1995; Slevin et al., 1988. In C. King, & P. Hinds, 1996).

According to Raphael et al. (1996), there are some issues in measuring quality of life: these are whether focus should be on objective (e.g., medical status, mobility, quality of housing, etc.). Another issue whether data should describe and be collected from individuals (micro-level data) or describe the functioning of the systems (e.g., income distribution, availability of health services, etc.). Another question is whether measures should be explicitly value-laden (e.g., personal control and independence are fundamental quality of life indicators) or value-neutral (e.g., personal control and independence may be desirable for only some individuals).

*Benefits of QOL measurements:* When adequately measured, QOL has been used to distinguish different patients or groups of patients, to predict individual outcomes, and to evaluate the effectiveness of therapeutic interventions. In addition, QOL evaluation has a number of potential uses in aiding routine clinical practice: it can help physicians to prioritize problems, to communicate better with patients, to screen for potential adversities, and to identify patients' preferences (Berlim and Fleck, 2003).

There is another specific area of QOL that is health-related quality of life (HRQOL). This area of assessment seeks to evaluate the individual's health-related quality of life, i.e., the impact of an individual's health status on his ability to function in the important domains of his life. Overall, HRQOL includes the patient's sense of his well-being within the multiple domains of psychological, social, and physical functioning, as well as the disease-specific domain, which reflects one's sense of how a specific disease is uniquely impacting function in those three domains (Trief et al., 2002). For individuals with diabetes, Polonsky (2000) eloquently describes HRQOL as "a formalized way of talking about the personal side of diabetes, the felt burden of living with the illness, how diabetes can get in the way of living a rich, full life."

From the perspective of patients, Smith (1999) has differentiated QOL from perceived health status. He found that QOL and health status are distinct constructs. When rating QOL, patients give greater emphasis to mental health than to physical functioning. This pattern is reversed for appraisals of health status, for which physical functioning is more important than mental health. As a conclusion, quality of life and health status are distinct constructs, and that the two terms should not be used interchangeably.

**Instruments of measuring QOL:** Global, generic, and specific instruments represent three different types of measures for the assessment of quality of life (Wiklund et al., 2000):

*Global measures* are those designed to measure quality of life in the most comprehensive or overall manner. This may be a single question that asks the person to rate his/her overall quality of life or an instrument such as the Flanagan Quality of Life Scale that asks people to rate their satisfaction on 15 domains of life.

*Generic measures* have much in common with global measures and were designed primarily for descriptive purposes. In health care they delineate as comprehensively as possible the full impact of a disease or its symptoms on the patient's life. Generic measures are applicable to a wide range

of populations (e.g., WHOQOL-BREF instrument). The main advantage is their broad coverage and the fact that they allow comparisons of different patient populations or across studies. A disadvantage is that they may not address topics of particular relevance for a given disease.

*Disease Specific measures* were developed to monitor the response to treatment in a particular condition. These measures are confined to addressing the problems of selected patient groups. They tend to have high sensitivity to change but often lack a conceptual link to quality of life definitions (e.g., Diabetes Quality of Life Measure (DQOL), Diabetes Care Profile (DCP)).

*Dimension Specific measures* focus on a particular problem within a patient group such as pain, fatigue, physical functioning. These measures are useful for monitoring specific problems that are to be addressed by an intervention.

Instruments may also vary in the method of administration. Standardized questionnaires allow uniform administration and unbiased quantification of data, as the response options are predetermined and thus equal for all respondents. Increasingly, the emphasis has been on self-administered questionnaires. However, these may exclude certain groups of patients, for example, those who cannot read or write, the elderly, and those with severe somatic conditions. Another problem is that the use of self-administered questionnaires can mean the possible loss of data if patients do not fill out every question. Quality control can minimize this problem.

Interviews have the advantages that most patients can be assessed and the completeness of the data is ensured. These advantages tend to be outweighed by the disadvantages of time and expense (Wiklund et al., 2000).

### **5.6.2 Quality of life and DM**

In this subsection, it will be demonstrated how diabetes mellitus can negatively affect QOL through compromising physical function, sexual life, neurocognitive abilities, life expectancy, family roles, social relationships and psychological health. Moreover, it will be discussed how intensive treatment of diabetes disrupts the overall QOL.

Type 2 diabetes is a chronic disease that affects a patient's general health and well-being in various ways. Several studies have demonstrated that diabetes can negatively affect HRQOL (Rubin and Peyrot, 1992). For example, severe dietary restriction and daily self-administration of oral medications or insulin may adversely affect an individual's health-related quality of life

(HRQOL). In addition, the long-term complications of diabetes, such as nephropathy, neuropathy, heart disease, and stroke, with their considerable impact on health, may also have a negative effect on quality of life, as shown in the U.K. Prospective Diabetes Study (UKPDS) study (UKPDS, 1999; Rubin & Peyrot, 1999)

Diabetes can compromise physical function [e.g., development of complications (Lloyd et al., 1992)], psychological status [e.g., depression (Lustman et al., 2000)], and social relationships [e.g., interpersonal conflict (Nouwen et al., 1997)].

#### **5.6.2.1 Complications and QOL:**

In a study was to describe the health utilities associated with diabetes and its treatments, complications, and comorbidities. Major diabetes complications (blindness, dialysis, symptomatic neuropathy, foot ulcers, amputation, stroke, and congestive heart failure) were associated with more substantial reductions in quality of life (Coffey et al., 2002).

In the U.S., blindness, kidney failure, amputations, and cardiovascular disease resulting from diabetes not only markedly reduce quality and length of life but also cost nearly \$100 billion annually (Fleming et al., 2001; American Diabetes Association, 1998).

Edelman et al. (2002) conducted a study to determine the effects of a new diagnosis of diabetes, on patients' health-related quality of life (HRQOL) 1 year after diagnosis. They found no association between unrecognized diabetes and HRQOL. This finding is in agreement with most published studies in diabetes and HRQOL. In this study, in which patients are diagnosed with diabetes earlier in the course of their disease, most patients will not have complications. Therefore, we observe that in our sample, comorbidity is the primary determinant of HRQOL. This is not surprising, because complications and comorbidities are the primary determinant of HRQOL in patients with diabetes, and complications are unlikely to develop within 1 year of the early diagnosis of diabetes.

#### **5.6.2.2 Physical function and QOL:**

Threats of physical disability, loss of independence, and diminished quality of life may ultimately be the greatest concern for many with diabetes. Functional disability leads to loss of independence and predicts future hospitalization, institutionalization, and death (Mor et al., 1994). Diabetes-related foot complications result in an enormous patient burden. Patients with diabetes and foot ulcers are at risk for hospitalizations, lower extremity infections, and amputations. Both

foot ulcers and amputations result in decreased function, lowered quality of life, and increased health care costs (Wrobel et al., 2003).

The results of a study (Gregg et al., 2002) conducted to examine the relationship between diabetes and the incidence of functional disability and to determine the predictors of functional disability among older women with diabetes, show that, diabetes remained associated with a 42% increased risk of any incident disability and a 53-98% increased risk of disability for specific tasks, which are likely to further erode health status and quality of life.

A recent study (Wu et al., 2003) designed to examine the impact of diabetes on change in self-reported functional status over a 2-year period among older Mexican Americans with diabetes, showed that, presence of diabetes and associated complications may lead to a significant decline in functional status among these patients. The prevalence of functional limitations among diabetic subjects was found to be nearly two times higher than that among non-diabetic subjects in our study. These results also indicated that both diabetes-related complications and a longer duration of diabetes contribute to the increase in functional decline among these subjects.

Another study (Volpato et al., 2002) conducted to elucidate the role of diabetes-related impairments and comorbidities in the association between diabetes and lower extremity function in a sample of disabled older women shows that, women with diabetes significantly had a greater prevalence of mobility disability, activities of daily living disability and severe walking limitation, and their summary mobility performance score was lower than in non-diabetic women. These results reinforce the role of diabetes in the disablement process of older individuals, which negatively affect their QOL.

According to a study conducted by Ryerson et al. (2003) people with diabetes had a higher proportion of any physical limitation than did people without diabetes overall. In a nationally representative sample of U.S. adults, 66% of adults with diabetes (6.9 million people) had difficulty doing at least one of the physical tasks that have been assessed. Those tasks involving mobility or lower extremity function, such as stooping, standing, walking, pushing, and climbing, tended to be the most problematic for people with diabetes and had the highest prevalence of any limitation. Thus, disability is considered a key indicator of the degree of morbidity associated with a chronic disease such as diabetes and a core component of the impact of chronic disease on quality of life.

Gregg and Brown reviewed (2003) the researches associating diabetes with aging-related complications. They found that, evidence has been growing that diabetes is associated with increased risk of physical disability, falls and fractures, and other conditions associated with geriatric syndromes. For example: in the Third National Health and Nutrition Examination Survey (NHANES III), women and men aged 60 years or more with diagnosed diabetes were 2-3 times more likely to be unable to walk one-fourth of a mile, climb stairs, and do housework than similar-aged adults without diabetes. Women with diabetes also had significantly slower walking speed, worse balance, and a 58% higher likelihood of falling than did non-diabetic women. In another prospective study of women in the Study of Osteoporotic Fractures, women with diabetes had twice the yearly incidence of becoming unable to walk one-fourth of a mile, doing heavy housework, or preparing meals. Schwartz et al. found that, although women with type 2 diabetes had a significantly higher bone mineral density than did non-diabetic women, the increased risk of falls (53% greater risk of at least one fall per year) apparently outweighed this advantage, resulting in a 49% increased risk of fractures.

In summary, patients with diabetes are two to three times more likely to report disability than their non-diabetic counterparts (Tucker et al., 2000; Gregg et al., 2000). Diabetes as a chronic disease significantly limits daily activity in 60% of diabetic people >65 years of age compared with only 33.5% of those without diabetes (Adams & Benson 1993). This in turn leads to disability, diminished quality of life, and an increase in the economic burden for these individuals and society at large.

### **5.6.2.3 Sexual life and QOL:**

Diabetes is known to cause multiple psychological and sexual problems (Thomas & LoPiccolo, 1994). Erectile dysfunction (ED) is a well-established complication of diabetes, and it is associated with reduced quality of life among these men (De Berardis et al., 2002). Diabetic **men** are three times as likely to develop ED as non-diabetic men and prevalence estimates of ED among diabetic men range from 35 to 70% (Siu et al., 2001; Fedele et al., 2000; Bacon et al., 2002; Veves et al., 1995; Fedele et al., 2000; Hakim and Goldstein, 1996; Constance et al., 2002; Chew et al., 2000; Jackson, 2004). The cause is multifactorial, but most commonly reflects endothelial dysfunction and autonomic neuropathy. Diabetes and vascular disease often coexist and ED may be a marker for silent occlusive arterial disease, for which the patient should be

screened. Female Sexual Dysfunction or Disorder (FSD) is more difficult to define; these include problem with arousal, lubrication and orgasmic dysfunction (Jackson, 2004).

Therefore, routine questioning by health care professionals is an important part of the overall management because of the deleterious effect of ED on relationships, self-esteem and quality of life.

According to National Institutes of Health (NHI) Consensus Development Panel on Impotence, (1993), the presence of a normal sexual desire and the inability to physically act on that desire can affect patients' lives in different ways, including disorders in interpersonal relationships, interference with sexual life, problems with partners, and increase in mental stress, making ED a major quality of life issue.

The results of a study (Berardis et al., 2002), conducted to assess the prevalence of self-reported erectile dysfunction and evaluate its impact on quality of life within the context of a large, nationwide outcomes research program in type 2 diabetes, revealed that 34% of the patients reported frequent erectile problems, 24% reported occasional problems. Erectile dysfunction was associated with higher levels of diabetes-specific health distress, worse psychological adaptation to diabetes, a dramatic increase in the prevalence of severe depressive symptoms, lower scores in the quality of life scale, and a less satisfactory sexual life. As a conclusion of this study: erectile dysfunction is extremely common among type 2 diabetic patients and is associated with poorer quality of life, as measured with generic and diabetes-specific instruments.

In a study (Penson et al., 2003) to compare disease-specific health-related quality of life (HRQOL) and severity of erectile dysfunction (ED) in impotent men with and without diabetes, it is found that diabetic impotent men reported worse erectile function and intercourse satisfaction at baseline, and ED had a greater impact on their emotional life. Diabetic men with ED had significantly different trends over time in the erectile function, intercourse satisfaction, sexual desire, overall satisfaction, and the sexual experience-psychological impact domains. The aim of a study conducted by Bacon et al. (2002) was to examine the effects of type and duration of diabetes on erectile function in men >50 years of age compared with men of similar age in a large well-defined sample of men. In this large cohort of men aged 53-90 years, they found that the risk of ED steadily increased with duration of type 2 diabetes to a nearly twofold greater risk compared with men without diabetes. For middle-aged and older men with type 2 diabetes, the risk of ED was approximately three times higher than that for men of similar age without diabetes.

The most common sexual dysfunction in **women** with diabetes is decreased sexual arousal with slow and/or inadequate lubrication and more pain on sexual intercourse (Koch and Young, 1988). Enzlin et al. (2002) conducted a study to 1) examine the prevalence of sexual problems in women with type 1 diabetes, 2) study the influence of diabetes-related somatic factors on female sexuality, and 3) study the influence of psychological variables on the sexual functioning of this group. The results of this study are: More women with diabetes than control subjects reported sexual dysfunction. Women with more complications reported significantly more sexual dysfunctions. Diabetic women with sexual dysfunction mentioned lower overall quality of the marital relation and more depressive symptoms than their respective counterparts in the control group.

Women with type 1 diabetes are likely to report menstrual disorders, including a later age at menarche. Type 1 diabetes is thought to disrupt normal hypothalamic-pituitary-gonadal function, particularly if the disease is poorly controlled, and thereby affects menstrual cycles and other reproductive outcomes (Cawood et al., 1993). Another study (Strotmeyer et al., 2003) was conducted to determine whether women with type 1 diabetes have a greater prevalence of menstrual irregularities (including cycle length, menstruation length, and heavy menstruation) across the reproductive lifespan. The results showed that women with type 1 diabetes had more menstrual problems (long cycles, long menstruation, and heavy menstruation) before age 30 years than sisters and control subjects. Women with type 1 diabetes experienced later menarche, earlier natural menopause, fewer pregnancies, and more stillbirths than women without diabetes. These menstrual characteristics may impact quality of life and reproductive health for women with type 1 diabetes

Newman and Bertelson's (1986) study was methodologically very good and revealed that 47% of participating women reported sexual dysfunction. In order of importance, these women reported decreased sexual arousal (lubrication) (32%), decreased sexual desire (21%), pain disorders (dyspareunia) (21%), and problems with orgasm (15%). Eighty-nine percent of these women reported that their problems occurred after their diagnosis of diabetes. Again, this study found no association between sexual dysfunction and diabetes complications.

Enzlin and associates (2003) revealed important evidence that women with diabetes are at increased risk for sexual problems. This evidence suggested that women with diabetes not only are prone to experience a decrease in sexual desire and more dyspareunia during sexual intercourse, but also are more likely to experience a decrease in sexual arousal involving slow or



inadequate vaginal lubrication. Given these findings, this study confirms the hypothesis that, just as diabetic men are at higher risk for erectile dysfunction, so too are diabetic women at higher risk for sexual dysfunction in which the arousal phase is predominantly affected.

#### **5.6.2.4 Psychosocial impact and QOL:**

Substantial literature documents the prevalence and course of psychiatric disorders, particularly affective and anxiety disorders, in adults and children with diabetes. Research findings have demonstrated that depression and anxiety disorders are more common in patients with diabetes than in the general population and linked with poor glycemic control. Studies also indicate that eating disorders such as bulimia are common in adults with diabetes, especially young women with type 1 diabetes.

In a study (Trief et al., 1999) to evaluate quantitatively whether the work environments of adults with diabetes relate to the adequacy of metabolic control and/or to the individual's adaptation to diabetes and to explore qualitatively the interactions between an individual's life at work and ways of coping with diabetes, it is found that, for insulin-treated adults with diabetes, interview themes showed that for a minority (18%), diabetes affected choice of work and that for a majority (60%), diabetes affected relationships at work and raised financial/job concerns (49%).

According to Guthrie et al. (2003) diabetes in infants, toddlers, older children, and adolescents poses serious physical, mental, and emotional challenges. The psychosocial impact of diabetes in childhood is ubiquitous and involves the entire family, as well as schools and society as a whole. Family members often experience the classic stages of grief, progressing from anger and denial to bargaining, depression, and finally resolution or acceptance. Unresolved grief leads to families becoming dysfunctional if they were not already so. Adjustment to a diagnosis of diabetes takes 6-9 months for children and 9-12 months for parents. Diabetes control and usual family functioning are difficult during this period and require support from the medical team.

A study (Castro et al., 2000) using the Child Behavior Checklist to determine whether having diabetes as a child affects psychological adjustment found that both internalized and externalized behavior problems were increased in children with diabetes. Boys with diabetes became more aggressive than boys without diabetes.

Depression: Adults with type 2 diabetes are 50-250% more likely than those without diabetes to suffer from depression. Depression may be attributable to hyperglycemia, diabetes-related health complications, or more broadly, the stress of living with a chronic health condition (Anderson et al., 2001, Lustman et al., 2000 & de Groot et al., 2000 In Fabricatore, 2003). On the other hand, poor diabetes control might cause or exacerbate depression via direct effects on brain functions or indirectly through complications, functional impairment, or decreased quality of life (Talbot F & Nouven, 2000). A number of studies, including meta-analyses, have shown the association between diabetes and depression (Lustman et al., 2000; Anderson et al., 2001; Egede et al., 2002; Egede et al., 2003; Eaton, 2002; Brown et al., 2004; Fisher et al., 2001; Cox, 1992). This indicates that many diabetic patients suffer from depressive symptoms, which have a great impact on the individual's functional ability and quality of life.

A study (Goldney et al., 2004) aimed to assess the prevalence of diabetes and depression and their associations with quality of life using a representative population sample in South Australia, revealed that, the prevalence of depression in the diabetic population was 24% compared with 17% in the non-diabetic population. Depression is found to have a severe negative impact on quality of life.

In a study (Anderson et al., 2001) to estimate the odds and prevalence of clinically relevant depression in adults with type 1 or type 2 diabetes, both clinicians and epidemiologists can expect individuals with diabetes to be twice as likely to be depressed as non-diabetic individuals in similar settings. Aggregate estimates based on all of the eligible studies indicate that major depression and elevated depression symptoms were present, respectively, in 11 and 31% of individuals with diabetes. The odds of depression were significantly higher in women than in men with diabetes. Thus, as many as one in every three individuals with diabetes has depression at a level that impairs functioning and quality of life, adherence to medical treatment, and glycemic control. The same meaning has been explicitly located in the study of Egede et al. (2002) to ascertain the odds of diagnosed depression in individuals with diabetes and the relation between depression and health care use and expenditures. He found that individuals with diabetes were twice as likely to have clinical depression as a comparable sample from the general U.S. population.

Anxiety: In a study (Kruse et al., 2003) to determine the relationship between mental disorders and diabetes in a representative community sample, Kruse et al. found that, people with diabetes

had an increased prevalence of current anxiety disorders but not of somatoform and substance abuse disorders.

Other study was conducted by (Thomas et al., 2003) to determine whether type 2 diabetes contributes to the presence of depressive and anxiety disorder diagnoses in low-income adults with hypertension, asthma, and/or arthritis. The results indicate that the contribution of the diagnosis of type 2 diabetes is associated with increased depressive and/or anxiety disorder diagnoses in a sample of low-income adults seen in primary care clinics.

#### **5.6.2.5 Neurocognitive and QOL:**

Neurocognitive deficits have been observed in adults with type 1 diabetes, particularly those with at least five episodes of severe hypoglycemia and in patients with peripheral neuropathy. Among older adults with type 2 diabetes, cognitive deficits have been reported in association with poor glycemic control. In addition, research has shown that quality of life is diminished when diabetes-specific health behaviors are associated with a sense of burden (Delamater et al., 2001).

Asimakopoulou and Hampson (2002) reviewed the evidence for deficits in cognitive functioning in older people with diabetes and considered the implications for diabetes self-management. They found that Type 2 diabetes has been associated with an increased risk of developing dementia or Alzheimer's disease. Large prospective studies (Leibson et al. 1997 & Ott et al., 1999) have provided strong evidence that older people with diabetes are at a significantly higher risk of developing all types of dementia and Alzheimer's disease. Although the exact pathogenic mechanism is unclear, it has been proposed that diabetes doubles the risk of developing dementia and this is particularly true for people controlling the illness with insulin rather than OHAs.

Gregg and Brown summarized (2003) the studies, which link DM with the cognitive declines. They found that several large prospective studies have associated diabetes with cognitive decline and clinical dementia during the past 5 years. Four other studies found a significant association between diabetes and rate of cognitive decline. Two of these studies found a 60-100% greater risk of cognitive decline among people with diabetes than among those without diabetes. At least three studies have found diabetes to have a 50-200% greater risk for overall dementia and Alzheimer's disease.

It is concluded that these less traditional complications are common and may be as damaging as the commonly recognized vascular outcomes of the disease to older diabetic people because of their direct influence on quality of life.

#### **5.6.2.6 Treatment and QOL:**

Intensive treatment of diabetes and dependence on insulin often disrupts the usual activities, requires disease-focused behaviors from the patients, and potentially impacts overall quality of life (Eiser & Morse, 2001; Brown et al., 2000).

A recent study (Franciosi et al., 2001) of Italian type 2 diabetic patients investigated the impact of self-monitoring of blood glucose (SMBG) on quality of life. The analysis showed that an SMBG frequency of at least one measurement per day was significantly related to higher levels of distress, worries, and depressive symptoms among non-insulin-treated patients. Frequency of at least one measurement a week was still significantly related to higher scores for diabetes health distress and diabetes-related worries. Jacobson et al. (1994) also examined the effects of type I and type II diabetes on patient perceptions of their quality of life. They found that, for type II diabetic patients, insulin treatment was associated with lower levels of satisfaction with diabetes and greater impact of diabetes on quality of life.

In a study conducted by Redekop et al. (2002) to estimate the health-related quality of life (HRQOL) and treatment satisfaction for patients with type 2 diabetes in the Netherlands and to examine which patient characteristics are associated with quality of life and treatment satisfaction, it is found that older age, female sex, insulin therapy, presence of complications, longer duration of diabetes, and obesity were associated with a lower HRQOL. Another recent secondary analysis of a mailed survey (Watkins et al., 2000) also found that diabetes-specific health behaviors such as dietary adherence might negatively affect quality of life by increasing the level of perceived diabetes-related burden.

#### **5.6.2.7 Family and QOL:**

Because diabetes affects not only the patients who have it but also their whole family, it needs to be addressed with the whole family in mind.

Northam and associates (1996) found that Australian families became less flexible over time in diabetes-related activities. Jacobson and associates (1994) noted in a 4-year prospective study that families with diabetes who participated in their study tended to be more dysfunctional than

families without diabetes. These families were confused about diabetes-related goals. They encountered more problems for girls caring for their diabetes than for boys (e.g., eating disorders or issues involving the starting of menstrual periods).

The results of a study (Laffel et al., 2003) to evaluate the Pediatric Quality of Life Inventory (PedsQL) self-report and parent proxy report of general quality of life in youth with type 1 diabetes of short duration showed that the parents of youth with type 1 diabetes reported a lower quality of life compared with parents from the non-diabetic sample. Children who reported higher diabetes-specific family conflict reported lower overall quality of life and lower physical functioning and psychosocial subscale scores; parental responses revealed similar trends.

In a study (Trief et al., 2001) to explore the relationship between marital relationship domains (i.e., intimacy and adjustment) and glycemic control and psychosocial adaptation to diabetes, it is found that, better marital satisfaction and higher levels of marital intimacy were related to better diabetes-specific and general quality of life.

According to the Report of the Psychosocial Therapies Working Group (Delamater et al., 2001), diabetes imposes considerable demands on children and their families. Diabetes can adversely affect both psychosocial and neurocognitive functioning, thus potentially affecting the quality of life of the child and the entire family. Research indicates that many mothers of newly diagnosed children are at risk for adjustment problems of their own, with significant depressive symptoms observed in approximately one third of mothers.

#### **5.6.2.8 Life expectancy and QOL:**

Manuel and Schultz, 2004 linked together databases that contain population-based mortality, morbidity, and diabetes prevalence in Ontario/Canada to estimate the HRQOL, life expectancy, and health-adjusted life expectancy (HALE) of people with and without diabetes. They found that life expectancy of people with diabetes was 64.7 and 70.7 years for men and women, respectively-12.8 and 12.2 years less than that for men and women without diabetes. HALE was 58.3 and 62.7 years, respectively, for men and women-11.9 and 10.7 years less than that of men and women without diabetes.

In a study (Riddle, 2004) conducted to estimate the lifetime risk of developing diabetes for people of various ages and the expected effects of diabetes on their life expectancy, the findings were striking. The lifetime risk of developing diabetes for an individual born in the United States in 2000 was estimated to be 33% for men and 39% for women. The predicted increase of mortality

rates after diagnosis of diabetes was also impressive. Children developing diabetes in 2000 at age 10 were predicted to live about 19 fewer years than they would have without diabetes. Assuming that diabetes reduces the quality as well as duration of life, the loss of quality-adjusted life years (QALYs) for such children was predicted to be 31 for boys and 33 for girls.

**As a summary:** Quality of life is an important health outcome in its own right, representing the ultimate goal of all health interventions. According to Rubin & Peyrot (1999), QOL is taken as a multi-dimensional construct comprising the individual's subjective perception of physical, emotional and social well-being, including both a cognitive component and an emotional component. Two broad approaches to HRQOL measurement have emerged - generic and disease-specific. People with diabetes have a worse QOL than people with no chronic illness, but a better QOL than people with most other serious chronic diseases. The relationships between the duration of diabetes and QOL are mixed. Several studies found that increased duration of diabetes was associated with decreased QOL, while some have found no significant association. Jacobson and colleagues found a connection between type of diabetes and QOL: Type 2 patients on insulin still experienced better HRQOL than type 1 patients. Results of research on the association between treatment regimen and QOL in people with diabetes are mixed, with some indication that increasing treatment intensity is associated with worsening of QOL. Other studies demonstrated that better glycemic control is associated with better QOL. Complications of diabetes, particularly the presence of two or more complications, are the most important disease-specific determinant of QOL and associated with worsened QOL. Numerous demographic and psychosocial factors influence QOL and should be controlled when comparing subgroups. A number of researchers have reported that QOL is better among diabetic men than among diabetic women; younger diabetics had significantly higher measuring scores than older diabetics in physical and social functioning, and lower scores than older persons in mental health. Methodologically, it is important to use multidimensional assessments of QOL, and to include both generic and disease-specific measures.

### **5.6.3 Impact of refugee status on QOL**

This subsection discusses the effect of the refuge experience, displacement, and uprooting on the quality of life of the refugees in general and of the Palestinian refugees in particular.

The United States Committee for Refugees (2003) reports that the total number of refugees and asylum seekers is 13.0 million, internally displaced persons is 21.8 million, the uprooted is 34.8 million, newly uprooted is 4.28 million, and the total number of involuntary repatriations is 102,000. It reports also that the global population of refugees increased by approximately 50% within the last five years.

Evidence shows that the proliferation of displaced persons commenced with independence were triggered by political, poor economic management, tribal and ethnic cleansing, military coups and religious cum ideological uprising (Russell, 1993; Gebresellasie, 1993). Since refugee flights are often volatile and unpredictable, fleeing often forces individuals and families to migrate with minimal personal belonging such as property and food. Such flights often involve risks of physical abuse and difficulty in integration with indigenous community in the country of asylum. This notion is best summarized by Jones (1983) who asserts that: breaking family, social, regional and national ties often bring hardship and grief particularly when forced. In new areas it creates conflicts, cultural and ethnic shock, making social adjustments difficult.

It is widely documented that refugees in an asylum country suffer different types of cultural shock. Exposure to different language, religion and custom that is alien often makes the process of acclimatization and acculturation in the new environment difficult. It should be emphasized that forced migrations affect an individual's personality, motivation, creativity, morale and confidence. The spatial concentration of refugees in settlement camps, shanty towns or slums is often associated with high risks of disease epidemics because of the overcrowding in areas with poor provision of infrastructural facilities such as piped water, health care facilities and so on (Ayiemba & Oucho, 1995).

According to Fox (1991), becoming a refugee, with its psychosocial, political and economic ramification, is a catastrophic life change. It is a series of losses, which include country, home, family members, and friends. Flakerud and Soldevilla (1989) reported that refugees are considered at risk because of the stresses of migration, relocation, separation from family, and loss of status and self-esteem experienced from discrimination encountered in the host country.

Uba and Chung (1991) showed that premigration traumas still affect the quality of refugees' lives several years later. In several cases, refugees were placed in camps where they faced the stress of overcrowding, poor food, unsanitary conditions and personal danger. However, camp conditions varied from country to country. In some cases, the refugees were treated as prisoners. The flight, internment and resettlement which all refugees experienced are stresses of catastrophic proportion that are major risks for mental health and lead to depression. Studies (Farias, 1991) have shown that the refugees live in continued traumatic situations which include: military violence, occupational abuse, threats of deportation, forced migration, social and economic marginality, family disintegration, economic loss, family breakdown and violence.

Sundquist et al. (1998) conducted a study to evaluate whether female Bosnian refugees have a poorer quality of life than Swedish women. A simple random sample of 120 women aged 18-59, born in Bosnia-Herzegovina with accepted refugee status, was interviewed. The control group for this was 292 Swedish women of the same age. The results of this study showed that, 38% of the Bosnian and 23% of the Swedes had bad global health. Bosnian women with bad global health had lower mean rankings than Swedish women, namely low quality of life in 'appetite', 'memory', 'leisure time', and aspects of mental well-being such as 'energy', 'patience', 'sleep', 'mood', and 'health'. They also had larger proportions of symptoms than Swedish women. It is concluded that Bosnian women irrespective of health status had poorer quality of life in most variables and more symptoms than Swedish women with good global health.

***The effect on the host countries:*** The greatest consequences of refugee movements affect not only the refugees themselves but also are endured by the host country. The crisis generated at the societal level by the influx of refugees has been aptly described by His Highness Prince Suddrudhin (Myers, 1993), the Aga Khan, who was a former United Nations High Commissioner for Refugees, as follows:

*“People flee their homes in search of food or jobs.... As the victims move, they carry their famine with them, much as they might carry an infectious disease. They impose intolerable burdens in terms of food requirements on the territory they enter. At the same time they flood the labor market, creating a slump in wages, and endangering the economic security of the local population. Fuse the two elements, and you have a perfect recipe for widespread human suffering, social disorder and political instability.”*



### **The Palestinian refugees and the Quality of life:**

According to United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA, 2004) report: one-third of the registered Palestine refugees, about 1.3 million, live in 59 recognized refugee camps in the area of operations in Jordan, Lebanon, the Syrian Arab Republic, the West Bank and Gaza Strip. The other two-thirds of the registered refugees live in and around the cities and towns of the host countries. Socio-economic conditions in the camps are generally poor with cramped living conditions and inadequate basic infrastructure such as roads and sewers.

The Gaza Strip is unique amongst UNRWA's five fields of operations as the majority of its population is refugees and over half of the refugees live in eight camps. Most of the camps do not have a sewerage system, and sewage and wastewater flow in open channels. Many roads and pathways in the camps are unsurfaced.

The refugee camps in Gaza Strip have one of the highest population densities in the world. For example, over 76,000 refugees live in Beach camp whose area is less than one square kilometer. It is crossed by hundreds of narrow sand-clogged alleys. Untreated sewage flows freely down them between the overcrowded shelter blocks. The perennial problem of flooding due to the topography and lack of a sewerage system has led to the sand being infected with parasites. Children have nowhere to play except in the sand and by the age of four, 85 per cent of children in the camp are infected with ascaris (round worm). The incidence of other intestinal parasites is alarmingly high. There is uneven distribution of health and care institution in Gaza strip; e.g., the refugees in the middle and south camps face many difficulties to obtain the desired health care services because most of health care settings are located in the north areas (UNRWA, 2004).

*Refugees International* (2003) reported that, quality of life for Palestinian refugees continues to spiral downward in response to on-going hardship, suppression, and displacement due to Israeli military occupation. The suffering of the Palestinian refugees is multifaceted that includes: restrictions on movement including construction of an enclosure, frequent curfews and seize, the increasingly pervasive and deepening poverty, the growing number of house demolitions, increasing unmet psychosocial needs, and the obstacles faced by humanitarian workers. The World Bank estimates that 60 percent of the Palestinian population is living in poverty, with the rate among refugees living in camps in Gaza strip estimated at 72 percent (November 2002). Per capita food consumption has fallen. In the past three years, the Israeli army has demolished more

than 3,000 homes and damaged thousands more, often destroying large areas of agricultural land and other public and private properties, and water and electricity infrastructure at the same time. More than 12,000 Palestinians have been made homeless by demolition or damage to some 1,668 homes (1,493 which belong to refugees) in the Gaza Strip. This hardship creates psychological stress that is largely overlooked. In addition to generalized trauma reactions, psychosomatic disorders are on the rise, particularly among children.

*Refugees International* (2003) reported also: Curfews and closures imposed on the West Bank by the Israeli military have hit the camps hard, since some residents are largely dependent on income from work inside Israel. As a result, unemployment has risen and socio-economic conditions in the camps have deteriorated further. There is generally inadequate infrastructure and socio-economic conditions in the camps are generally poor.

In a study conducted by Afana et al. (2002) to investigate the prevalence of post-traumatic stress disorder (PTSD) among patients in primary health care clinics in the Gaza Strip, a total of 661 patients were participated in the study. It is found that the overall prevalence of PTSD symptoms in primary health care patients was 29 percent, and significantly higher among females than in males.

A study conducted by the Gaza Community Mental Health Programme (GCMHP, 2001) on the prevalence of post-trauma stress disorders (PTSD) among children 10-19 years of age revealed that 32.7 per cent have suffered from acute level of PTSD which needed psychological intervention, 49.2 per cent suffered from moderate PTSD symptoms, 15.6 per cent of the children suffered from low level of PTSD and 2.5 per cent had no symptoms. In addition, the study indicated that children who are living in camps suffer more than children who are living in towns (84.1 per cent and 15.8 per cent respectively). These findings are alarming.

A March 2003 Save the Children Sweden and United Kingdom study noted that parents report that their children under five exhibit disturbing behavioral symptoms, including increased violence and aggression, lack of concentration, failure to eat properly and maintain good hygienic, bed-wetting and nightmares (Mousa & Madi, 2003).

According to a July 2003 joint study by Save the Children US and the Secretariat of the National Plan of Action for Palestinian Children, 90 per cent of parents reported that their children exhibit similar traumatic stress-related symptoms. With children constituting 40 per cent of the Palestinian population of the occupied territory, the impact of the ongoing humanitarian crisis is

cause for grave concern about the future. This feeling is further compromised by the fact that the caregivers - parents and teachers mainly- themselves are stressed and frustrated, having therefore less emotional and mental energy to provide the necessary psychosocial support to their children (Arafat, & Boothby, 2003).

A recent survey conducted by GCMHP (2001) during the second Intifada (Al-Aqsa) in the southern region of Gaza, including the southern refugee camps, among children between the ages of 3-16 years and mothers between the ages of 21-55 years showed that the prevalence of PTSD among children was 39 percent and 10 percent among mothers.

## **5.7 Summary of the literature review**

This chapter presented the available literature on refugees, diabetes, and quality of life. It discussed the emerging definition and new classification of diabetes based on the new WHO/ADA recommendations, which provide a more rational platform for phenotyping and choosing appropriate therapies for persons with diabetes. The complications, which are common, will challenge clinicians, health care systems, and public health organizations to identify effective ways of optimizing quality of life among older adults with diabetes. Because many developing countries already have high Type 2 diabetes prevalence and diabetes complications, there is an urgent need for strategies to prevent the emerging global epidemic of Type 2 diabetes.

It also discussed the relationship between the experience of being a refugee and the QOL and management of diabetes. The refugee status impairs the QOL of refugees in different ways.

This chapter highlighted the general problems faced by patients with diabetes in developing countries as they manage or deal with their chronic condition. The living conditions of the refugees add more challenges to successful management of diabetes and place those refugees at greater risk for complications and reduced QOL. Improving these conditions and providing patients with the basic management requirements, within the existing resources, might improve their health and functioning, their compliance and lead to better QOL for refugee patients. Furthermore, in order to fully understand the experiences of the diabetic refugees and assist them in managing their chronic conditions and improving their QOL, it is important to have knowledge of their management styles, their level of perceived QOL, their satisfaction with specific domains of living, and how those domains contribute to their global QOL and to their management of diabetes.

## **Chapter 6**

### **General purpose of the study, objectives, and hypotheses**

Based on the previous chapters: Introduction, background of the study, theoretical framework, and the literature review of the study, this chapter presents and formulates the general purpose of the study, aims and objectives, hypotheses, research questions and the definition of the terms.

#### **6.1 Purpose of the study**

The general purpose of the study was to assess and evaluate the HRQOL of the diabetic Palestinian refugees who live in the refugee camps in Gaza strip. This study sought an understanding of how the Palestinian refugees manage their diabetes mellitus and their daily activities under the difficult conditions of the refuge life in the camps; how they evaluate the health services provided for them in the camps and how this impacts the quality of their lives.

To achieve this purpose, two research steps have been implemented: 1) examining the effect of the refuge life on the QOL of the diabetic refugees by evaluating the differences in QOL among diabetic refugees who live in the camps and the diabetic non-refugees who live in the cities in Gaza strip; 2) examining the effect of DM on the QOL of the refuges by evaluating the differences in QOL among the diabetic refugees and the non-diabetic refugees who live in the camps.

#### **6.2 Aims and objectives of the study**

As this study was the first one to assess and evaluate the QOL among the diabetic refugees in Gaza strip, it aimed to: first, provide a general understanding of the experience of having and managing diabetes from the views of refugees in their camps and how this impacts on the quality of their lives; second, provide valid and reliable information that help in improving the QOL not only for the diabetic refugees but also for all diabetic non-refugees and non-diabetic refugees in Gaza strip.

#### **The specific objectives of the study were:**

- 1) To assess and evaluate the effect of the refuge life on the HRQOL of the diabetic refugees;
- 2) To assess the impact of DM on HRQOL of the diabetic refugees;

- 3) To compare between the quality of health services provided by UNRWA and the MOH for the diabetic patients in Gaza strip;
- 4) To identify the interrelationship between age, sex, income, level of education, duration of diabetes, and type of diabetes and HRQOL among the diabetic refugees; and
- 5) To determine the effect of the diabetic complications on the overall QOL of the refugees and non-refugees.

### **6.3 Study hypotheses**

The following hypotheses have been derived and verified in the study:

#### **6.3.1 Null hypothesis (statistical hypothesis)**

There is no difference between QOL of the diabetic refugees in the refugee camps and the diabetic non-refugees in the cities.

#### **Alternative hypothesis**

Diabetic non-refugees shows greater increase in QOL scores than the diabetic refugees who live in the refugee camps in Gaza strip.

#### **6.3.2 Null hypothesis (Statistical hypothesis)**

There is no difference between QOL of the diabetic refugees and the non-diabetic refugees who reside in the refugee camps in Gaza strip.

#### **Alternative hypothesis**

Non-diabetic refugees show greater increase in QOL scores than the diabetic refugees in the refugee camps.

#### **6.3.3 Null hypothesis (Statistical hypothesis)**

There is no relationship between the age, sex, income, level of education, duration of diabetes, and type of diabetes and the QOL of the diabetic refugees.

#### **Alternative hypotheses**

- Older diabetic refugees show greater decrease in QOL scores than younger diabetic refugees.

- Male diabetic refugees show higher QOL scores than the females.
- High-income and well-educated refugees show higher QOL scores than those who are low-income and non-educated.
- Type 2 diabetics show better QOL than Type 1 diabetics.
- Patients with long duration of diabetes have lower QOL scores than those with short duration diabetes.

#### **6.3.4 Null hypothesis (Statistical hypothesis)**

There is no difference between QOL scores of the diabetic refugees who developed complications and those without complications.

#### **Alternative hypothesis**

The diabetic refugees who developed complications have lower QOL scores than those who did not.

### **6.4 Research questions**

- 1) What are the effects of the refuge life (refugee status) on the QOL of the Palestinian diabetic refugees who live in the refugee camps in Gaza strip?
- 2) How does DM impact the QOL of the diabetic refugees who live in the refugee camps in Gaza strip?
- 3) What are the differences between the quality of health services provided by MOH and UNRWA for the diabetic patients in Gaza strip?
- 4) What is the relationship between age, sex, income, level of education, duration of diabetes, and type of diabetes of the refugees and the quality of their lives?
- 5) How do the diabetic complications affect the QOL of the diabetic refugees?

## 6.5 Definition of the terms

**Quality of life:** World Health Organization (WHO) defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

**Health-related quality of life (HRQOL):** the impact of an individual's health status on his ability to function in the important domains of his life (Staquet et al., 1998). HRQOL has been defined as a multidimensional construct (Bowling, 2000). It includes the patient's sense of his well-being within the multiple domains of psychological, social, and physical functioning, as well as the disease-specific domain, which reflects one's sense of how a specific disease is uniquely impacting function in those three domains (Paula et al., 2002).

**A refugee:** According to the 1951 Geneva Convention (OHCHR, 1951) relating to the Status of Refugees (the Refugee Convention), the term refugee is applied to a person who owing to well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his (/her) nationality and is unable or, owing to such fear, is unwilling to avail himself (/herself) of the protection of his (/her) country; or who, not having a nationality and being outside the country of his(/her) former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.

**A Palestinian refugee:** Any person born in Palestine or to parents of Palestinian decedents who was forced to leave Palestine, either to another country or to a refugee camp within Palestine, during or after the 1948/1967 wars that resulted in the Israeli occupation of Palestine, and he could not return due to the practices of Israeli forces. They live in and outside Palestine, in and outside refugee camps (Al-Halabi, 1996).

**UNRWA:** the United Nations Relief and Works Agency for Palestine Refugees in the Near East, was established by United Nations General Assembly resolution 302 (IV) of 8 December 1949 to carry out direct relief and works programs for Palestine refugees. The Agency began operations

on 1 May 1950. Today, UNRWA is the main provider of basic services - education, health, relief and social services - to over 4.1 million registered Palestine refugees in the Middle East.

**A refugee camp:** A camp, according to UNRWA's working definition, is a plot of land placed at the disposal of UNRWA by the host government for accommodating Palestine refugees and for setting up facilities to cater to their needs. The plots of land on which camps were set up are either state land or, in most cases, land leased by the host government from local landowners. This means that the refugees in camps do not "own" the land on which their shelters were built, but have the right to "use" the land for a residence.

**Diabetes Mellitus (DM):** Diabetes mellitus is a group of metabolic diseases characterized by hyperglycemia resulting from defects in insulin secretion, insulin action, or both.

**Type 1 Diabetes:** Characterized by beta cell destruction, usually leading to absolute insulin deficiency. It has two forms: Immune-mediated diabetes mellitus: results from a cellular mediated autoimmune destruction of the beta cells of the pancreas. Idiopathic diabetes mellitus: refers to forms of the disease that have no known etiologies.

**Type 2 Diabetes:** Disease of insulin resistance that usually have relative (rather than absolute) insulin deficiency. It can range from predominant insulin resistance with relative insulin deficiency to predominant insulin deficiency with some insulin resistance.



## **Chapter 7**

### **Methodology**

#### **7.1 Study design**

The aim of this study was to determine the impact of the DM and the refuge life on the HRQOL of the Palestinian diabetic refugees and to compare it with overall QOL scores of the diabetic non-refugees and the non-diabetic refugees in Gaza strip. To achieve this purpose, quantitative and qualitative approaches have been used. Namely, a cross-sectional paired matched case-control design recommended by several researchers (Smith, Fear, Law, & Roman, 2004), combined with intensive interviews, was adopted for this study.

In this design, patients who have the disease and a group otherwise similar people who do not have the disease are selected. The researcher then looks backward in time to determine and assess the factor of interest (e.g., QOL) in the two groups. The case-control design has become a common and important method used to study many epidemiological and clinical questions (Fletcher et al., 1996). This design has several advantages: first, the investigator can identify cases unconstrained by the natural frequency of the disease and yet can still make a comparison. Case-control studies are relatively inexpensive and easy to assemble large number of cases from hospitals or community health centers, and similar groups without the disease and compare the past experience under study. A real advantage of the case-control study is its ability to address important questions rapidly and efficiently as long as their results are valid and reliable.

Also, data were obtained through intensive interviews with some of the diabetic refugees in the refugee camps. This qualitative method provides the refugee an opportunity to describe their experience with diabetes under the refuge conditions in the camps and enable the researcher to collect more in-depth information regarding some points in the QOL domains within the sociocultural context of the refugee camp.

In this study, three groups have been assembled: one case group and two control groups. The case group consisted of 197 diabetic refugees randomly selected from three refugee camps in Gaza strip. The first control group also consisted of 197 age-matched and sex-matched diabetic non-refugees and was selected from three neighboring cities in Gaza strip to be compared cross-sectionally with the cases to determine the effect of the refuge life on the QOL among the

diabetic refugees. The second control group consisted of 197 age-matched and sex-matched non-diabetic refugees and was selected from the same three refugee camps to assess the impact of DM on the QOL among the diabetic refugees.

This strategy of choosing more than one control group is an efficient method to guard against the difficulties attending the selection of truly comparable control groups and against a systematic error in the odds ratio, which may arise from the selection bias.

## **7.2 Setting of the study**

This study focused on the Palestinian refugees live in refugee camps in Gaza strip. According to the latest UNRWA statistics (December, 2003), more than 932,000 registered Palestinian refugees live in Gaza strip in and outside eight recognized refugee camps. These camps are distributed to the North of Gaza strip such as Jabalia and Beach camps; to the mid-zone of Gaza strip such as Nuseirat, Bureij, Maghazi, and Deir el-Balah camps; and to the south of the Gaza strip such as Khan Younis, and Rafah camps. About 45% of the refugees reside in the north of Gaza strip, 20% in the middle, and 35% in the southern area. Socio-economic conditions in the camps are generally poor with a high population density, cramped living conditions and inadequate basic infrastructure such as roads and sewers.

In order to choose a representative sample for the study, the biggest three refugee camps have been identified: Jabalia in the North, Nuseirat in the Middle, and Rafah in the South.

First, **Jabalia camp** is located north of Gaza City beside a village of the same name. The camp was established after the 1948 Arab-Israeli conflict for 35,000 refugees who had fled from villages in southern Palestine. The refugees were at first provided with tents, which UNRWA later replaced with cement block shelters with asbestos roofs. The registered refugee population in the camp is 103,646 persons. The camp covers an area of 1.4 sq. km. The shelters, which usually consist of two or three small rooms, a small kitchen and bathroom on an area of maximum 40 sq. m, are packed closely together. Narrow alleys and pathways, some less than one meter wide, run between the shelters. The camp lacks basic infrastructure. The first Palestinian Intifadah started in Jabalia camp in December 1987. Prior to the closure of the Gaza Strip in September 2000 most of the refugees worked as laborers in Israel or locally in agriculture on nearby farms in Beit Lahia. Some own small shops in the camp and a few works in small businesses. The UNRWA's health center provides primary health care and is run by 70 health

care workers assigned to morning and afternoon shifts. On average, 23,785 consultations are held there each month.

Second, **Nuseirat camp** is located 8 kms south of Gaza City. About 16,000 refugees settled in the camp after the 1948 Arab-Israeli conflict, most having fled from the Beersheva area in the Negev in southern Palestine. Many were housed initially in a former British military prison (Kallaboush) and others were sheltered in tents. The poorest section of the camp is known as the "new camp" or Block J. The registered refugee population in the camp is 64,233 persons. Part of the camp lacks a sewerage network and sewage and wastewater flows in open channels along roads and pathways, as well as through agricultural lands toward Wadi Gaza, thus posing a serious health hazard. Prior to the closure of the Gaza Strip in September 2000 most of the refugees worked as laborers in Israel or locally in agriculture. The UNRWA's health center, which was built in 1963, is staffed by 43 health care workers assigned to morning and afternoon shifts. On average, 18,591 consultations are held there every month.

Third, **Rafah camp** is the southern-most camp and is located on the Egyptian border. The camp was established in 1949 to house 41,000 refugees. At that time it was the largest and most concentrated population of refugees in the Gaza Strip. However, several thousand residents have since moved from the camp to a housing project in nearby Tel es-Sultan. The registered refugee population in the camp is 90,638 persons. It is divided into 17 blocks; about 20 percent of the shelters have concrete roofs and 80 percent have asbestos roofs. Since the start of the second *Intifada (The Uprising)* in September 2000, Rafah camp has suffered from a campaign of demolitions by the Israeli military along the Egyptian border. Several hundred families have been made homeless. The UNRWA's health center is staffed by 66 health care workers and assigned to morning and afternoon shifts. On average 22,412 consultations are held there each month. In 1995, a new Agency health center was constructed in the Tel es-Sultan housing project; it is staffed by 20 health care workers and average of consultations per month is 7,102 (UNRWA, 2003).

In addition to the three camps, other three neighboring cities have been identified, from which one control group (197 diabetic non-refugees) has been selected. These three cities are: Gaza in the north, Deir El-Balah from the middle and Rafah from the south. Choosing three neighboring cities, from which the matched control subjects have been selected, is very crucial to decrease the selection bias.

The diabetic refugees (case group) have been recruited from UNRWA clinics in the three camps (Jabalia, Nuseirat, and Rafah) where the subjects used to make a follow-up health care, while the diabetic non-refugees (the first control group) have been selected from the MOH's primary health care centers in Gaza, Deir El-Balah, and Rafah cities.

### **7.3 Period of the study**

The fieldwork and collection of the data in Gaza strip took place from November 2003 through December 2004. Upon the arrival of the investigator to Gaza strip, he contacted experienced co-researchers and trained them how to recruit the subjects for the study, how to conduct the interviews and how to distribute the questionnaire.

During this period, the field work encountered some interruptions and delays as a result of the security measures imposed by the occupation around and among the Palestinian camps and cities such as frequent military raids in the Palestinian Territories, long-standing closure in and outside the cities, etc. These measures have sometimes prevented the interviewers to reach the subjects in their clinics or at homes.

### **7.4 Study population**

The study population is the entire number of cases that meet specific eligibility criteria. In this study, the population was all the Palestinian refugees who suffer from diabetes mellitus (Type 1 and Type 2) and still live in the refugee camps in Gaza strip.

### **7.5 Sample and sampling techniques**

The study sample consisted of three groups: one case group and another two control groups. Because the population of the study is distributed unequally in Gaza strip, the investigator has stratified the population according to their living places (45% of the refugees live in the north, 20% live in the middle, and 35% in the south). Then the investigator decided to select the numbers of the subjects in proportion to the size of the stratum in the population (table 9). This method is called a probability proportionate stratified sampling. According to Pilot et al. (1995), stratified sampling can guarantee a great degree of representativeness of different segments of the population.

Group	North-zone		Mid-zone		South-zone		Total	
	N	%	N	%	N	%	N	%
<b>Diabetic refugees</b>	89	45	39	20	69	35	197	100
<b>Diabetic non-refugees</b>	89	45	39	20	69	35	197	100
<b>Non-diabetic refugees</b>	89	45	39	20	69	35	197	100

**Table (9): Distribution of the study sample according to the area of residence**

Accordingly, 197 diabetic refugees as a case group (104 males and 93 females) were recruited from the UNRWA clinics in the selected three refugee camps as seen in table (9): 45% of the cases (no. 89) were from Jabalia UNRWA Clinic (located in the north of Gaza strip); 20% of the cases (no. 40) from Al-Nuseirat UNRWA Clinic (in the middle of Gaza strip); and 35% of the cases (no. 68) from Rafah UNRWA Clinic (in the south of Gaza strip). Two other control groups were selected based on paired 1:1 matching procedures; this means that for every case one control was assembled in every control group. Both control groups were matched for age, sex, and living places. Homogeneity and blocking were used to control extraneous variables. The first control group consisted of 197 diabetic non-refugees (104 males and 93 females) recruited from MOH's primary health care centers located in three cities: 89 participants from Gaza city in the north, 40 participants from Deir El-Balah city in the middle, and 68 participants from Rafah city in the south. These cities were selected in the neighborhoods of the refugee camps where the cases live to ensure that both cases and controls were selected from the same defined population. To maintain a high level of congruity between the groups, the second control group was recruited from the same refugee camps where the cases reside. It also consisted of 197 non-diabetic refugees (104 males and 93 females) distributed according to the living place as the same as the case group: 89 from Jabalia camp in the north, 40 from Al-Nuseirat camp in the middle, and 68 from Rafah camp in the south. This type of control selection is called non-hospitalized community or population control from which the cases arose (Schlesselman and Atolley, 1982).

For the qualitative methods, 33 diabetic refugees were randomly selected for the interviews. According to (Lofland and Lofland, 1984; Roberts and Burke, 1989), a sample size within the range of 20 to 50 interviews was judged sufficient for a qualitative study to elicit major, repetitive themes for the topic under study. The cases and controls met the same inclusion/exclusion criteria as the control subjects were selected based on the same sampling techniques as the cases.

### **7.5.1 Inclusion criteria**

#### ***A. For cases (diabetic refugees):***

1. A Palestinian refugee with diabetes and a resident of one of the three refugee camps chosen for the study.
2. A refugee over 20 years old.
3. The diabetes had been diagnosed and clinic follow-up implemented for at least six months.
4. The diagnosis had been confirmed by a physician and the patient was under medical management.
5. No other comorbidities (diseases) associated with diabetes.
6. The refugee was able to verbally communicate with the interviewer.
7. The refugee had time and was willing to participate in the study.

At the beginning of the study, a total number of 319 diabetic refugees (case), were randomly selected from the files of the patients in UNRWA clinics in the three refugee camps; 122 were excluded from the study: 67 subjects were suffering from other diseases, 19 did not come to follow up care in the clinic for more than 6 months, 7 women became pregnant during the period of the data collection, 7 refused to sign the consent form, 2 died, and 20 subjects participated in the pilot study. Those 20-pilot subjects were excluded mainly to prevent both interviewer and respondent bias due to asking and repeating the same questions.

#### ***B. For the first control group (diabetic non-refugees)***

Actually, the inclusion criteria for the diabetic non-refugees is similar to the case group except the subject must be non-refugees and reside in one of the three cities which were selected for the study (Gaza, Deir El-Balah, Rafah). 254 eligible subjects were randomly selected from the files in the MOH clinics in the three cities. All of these subjects were informed to participate in the study upon their follow-up visits in the clinics. 48 were excluded from the study because either they refused to participate from the beginning or they quit after giving their approval. Another 7 subjects were excluded by the investigator to equalize the number of the subjects as in the case group.

#### ***C. For the second control group (non-diabetic refugees)***

1. A Palestinian refugee without any chronic disease and a resident of one of the three refugee camps chosen for the study.

2. A refugee over 20 years old.
3. The refugee was able to verbally communicate with the interviewer.
4. The refugee had time and was willing to participate in the study.

This group was selected based on “snowball sampling” technique, which is a special non-probability method used when the desired sample characteristic is rare. It was difficult and time-consuming to locate respondents to match the case subjects. Snowball sampling relied on referrals from initial subjects to generate additional subjects. As the number of the respondents was equal to the case subjects, the investigator and his assistants have stopped this process.

### **7.5.2 Participants selection procedure**

After the permission to conduct the planned study was obtained from the concerned authorities, the investigator met with the physician and the nurse in charge of the UNRWA clinic, explained the purpose of the study and requested assistance from them in recruiting the subjects. The subjects who met the inclusion criteria were selected as study participants. The purpose, specific objectives and the method of the study were carefully explained to each eligible subject. When the subjects agreed to participate in the study, they were assured that they could withdraw at any time and they would not be identified in the report of the study. The consent form (appendix A) was read to them at that time.

### **7.6 Data collection procedure**

In this study, quantitative and qualitative approaches to the collection and analysis of data were used. Face to face, semi-structured interviews were conducted to collect data from the cases and the controls by well-trained and experienced co-researchers. According to Lofland and Lofland (1984), the intensive interview aims to discover the participant’s experience of a particular situation. It further allows the researcher an opportunity to pursue the topics of interest in depth, to probe further topics which may arise during interviews, and to clarify misinterpretations which may occur. The co-researchers were chosen based on their experience and congruity with the sample characteristics, e.g., male refugee subjects were interviewed by male refugee interviewers, female refugees were interviewed by female interviewers, and so on. It is strongly recommended that the staff be hired to match the backgrounds of the subjects with respect to such characteristics as gender and cultural background, especially in our conservative community to prevent any bias in answering some culturally sensitive questions like “satisfaction with sexual

life”, etc. The investigator and his assistants met the eligible subjects to conduct the interviews and to fill the questionnaire either in the clinics of the UNRWA and the MOH or at home according to the mutual convenience.

### **7.6.1 Pilot testing**

The data collection package (The demographic information sheet and the QOL questionnaire) was pilot tested by 20 subjects from the case group (diabetic refugees), 20 subjects from the first control group (diabetic non-refugees), and another 20 subjects from the second control group (non-diabetic refugees). All of those pilot participants were excluded from the study. The goals for this pilot testing were to assess the adequacy of the data collection plan, to know whether respondents from all groups understand the questions in the same way, to identify any parts of the instrument that the subjects find objectionable or culturally incongruent, and to determine needs for further training of the data collection staff. Thus, revisions and refinements have been done to minimize the problems which may be encountered during the data collection.

### **7.6.2 Demographic information sheet**

This part of the data collection package was developed by the investigator himself to collect data about the participants and their family structure (Appendix B). This was developed following an extensive review of the available literature on diabetes mellitus, QOL and refugees in general. No references, research studies, or assessment tools were found about the population of interest (diabetic refugees). The demographic information sheet covered the following areas of interest: 1) Demographic data: gender, age, educational level, marital status, and residence place; 2) Socio-economic status: type of the house, occupation, income status, number of the dependent persons on the participant; and 3) Health profile: type and duration of DM, age at onset, type of treatment, complications or other chronic diseases.

### **7.6.3 Quality of life questionnaire**

WHO (1996) emphasized the importance of including both the objective conditions and the subjective experiences, which represent the quality of life where the inter-relationships between them are studied. For the purpose of this study, QOL was assessed using World Health Organization Quality of Life Questionnaire- short version (WHOQOL-BREF) (Appendix C). The WHOQOL-BREF is an abbreviated version of the WHOQOL-100 quality of life assessment. It produces scores for four domains (physical health, psychological, social relationships and



environment) related to quality of life (table 10). It also contains two other questions are examined separately: question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of their health. The four domain scores denote an individual's perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100 (WHO, 1996).

<b>Domain</b>	<b>Facets incorporated within domains</b>
1. Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration
3. Social	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

**Table (10): WHOQOL-BREF domains**

#### **7.6.4 Strengths of the WHOQOL instruments**

1) The WHOQOL instruments were developed internationally and cross-culturally: The WHOQOL was developed simultaneously in 15 field centers around the world. The important aspects of quality of life and ways of asking about quality of life were drafted on the basis of

statements made by patients with a range of diseases, by well people and by health professionals in a variety of cultures. The instrument was rigorously tested to assess its validity and reliability in each of the field centers and is currently being tested to assess responsiveness to change. The WHOQOL-BREF, an abbreviated 26-item version of the WHOQOL-100, was developed using data from the field-trial version of the WHOQOL-100. The WHOQOL instrument can be used in different cultural settings, at the same time results are comparable across cultures. 2) The WHOQOL instruments place primary importance on the perception of the individual: Most assessments in medicine are obtained by examinations by health workers and laboratory tests. The WHOQOL instruments, by focusing on individuals' own views of their well being, provide a new perspective on disease. For example, that diabetes involves poor body regulation of blood glucose is well understood, but the effect of the illness on the perception that individuals have of their social relationships, working capacity, and financial status has received little systematic attention. The WHOQOL instruments are tools that will enable this type of research to be carried out. They not only inquire about the functioning of people with diabetes across a range of areas but also how satisfied the patients are with their functioning and with effects of treatment (WHO, 1996).

#### **7.6.5 Psychometric properties of the WHOQOL-BREF instrument**

The WHOQOL-BREF has been shown to display good discriminant validity, content validity and test-retest reliability. The analyses undertaken in an international field trial of the BREF, which compiled data from 24 WHOQOL centers representing 23 countries worldwide, provide considerable validity evidence for the WHOQOL-BREF. Overall the instrument shows good factor structure. Each of the four domains appears to be both sensitive to the health status of respondents, and sensitive to change in health status following treatment. All four domains demonstrate good internal consistency and excellent test-retest reliability. The physical and psychological domains in particular also demonstrate good construct validity. The two global items (Item 1 and Item 2) demonstrate acceptable test-retest reliability. The overall QOL item appears to be sensitive to change in health status following treatment, while both individual items show good discrimination between well, ill and very ill populations. These findings are encouraging in terms of the use of these items as overall indicators of overall QOL.

### **7.6.6 The Uses of the WHOQOL-BREF instrument**

1) In medical practice: In clinical practice the WHOQOL-BREF instrument can be used to give valuable information that can indicate areas in which a person is most affected and help the practitioner in making the best choices in patient care. 2) Improving the doctor-patient relationship: By increasing the physician's understanding of how disease affects a patient's quality of life, the interaction between patient and doctor will change and improve. This gives more meaning and fulfillment to the work of the doctor and leads to the patient being provided with more comprehensive health care. 3) In health services evaluation: In the periodic review of the completeness and quality of medical services, the patients' concerns are of importance. The instruments provide an invaluable supplementary appraisal of health care services, by yielding a measure of the relationship between the health care service and patients' quality of life, and also by directly presenting a measure of patients' perception of the quality and availability of health care. 4) In research: The WHOQOL-BREF instrument provide new insights into the nature of disease by assessing how disease impairs or impacts the subjective well being of a person across a whole range of areas. 5) In policy making: When health providers implement new policies it is important that the effect of policy changes on the quality of life of people in contact with health services is evaluated. The WHOQOL-BREF instruments allow such monitoring of policy changes.

### **7.6.7 Translation of the WHOQOL-BREF questionnaire into Arabic**

The International Quality of Life Assessment Project (IQOLA) most recently has established a set of procedures for the translation and psychometric testing of the QOL tools. This process includes two forward translations of the original instrument into the new language, where the two independent translators meet to agree on a common version, which then is translated back into English by two other translators who also meet to agree on their version. Finally, these agreed upon versions are compared with the original and quality rated by two or more experts to assure “conceptual equivalence”, “colloquial language use” and “clarity” of the translations, so that the quality of the translation is explicitly assessed. A second step involves a piloting phase by applying the translated instrument to a convenient sample of people from the target nations who are then interviewed about the comprehensibility, feasibility and acceptance of the instrument (Shumaker & Berzon, 1995).

Translating and subsequent reliability testing of the questionnaire was conducted by the present investigator. The instrument was translated into Arabic to be used with people speaking Arabic in general, and with a sample of Palestinian refugees with diabetes in particular. For the purpose of this study, the investigator used the techniques suggested by (IQOLA) for translation. There are: back translation, and bilingual technique. The WHOQOL-BREF questionnaire was translated into Arabic by two independent translators. The investigator explained to each translator the importance of the independent translation in order to judge reliability. Each translation was compared and double checked for accuracy and the communication of Arabic meaning for the words. As the questionnaire translation was reviewed, the meaning, clarity and the appropriateness to the cultural values of the intended subjects were assured. After a careful investigation of the translations, they were synthesized into one form. The final Arabic version was then translated back into English by two Arabic physicians who were fluent in both the English and Arabic languages. Finally, when the two English versions were compared to validate the Arabic version, there was a high degree of equivalence and was subsequently used in this study.

## **7.7 Ethical considerations**

Formal approval to conduct the study at the UNRWA clinics and MOHs' primary health care centers in Gaza strip was obtained from the concerned authorities. The subjects in all groups who agreed to participate in the study were asked to sign the consent form. The participants and their families were assured that their names and responses would be confidential. All participants have been informed that the participation is entirely voluntary, and that even after the interview begins they can refuse to answer any specific questions or decide to terminate the interview at any point. They have been also informed that participation or non-participation or their refusal to answer questions will have no effect on services that they or any member of their families may receive from UNRWA or MOH.

## **7.8 Constraints and limitations of the study**

During the fieldwork in Gaza strip, the investigator and his assistants have encountered several difficulties in collecting the data, mostly regarding the unstable political situation. The uncountable checkpoints between the camps and the cities, the locked seize and closure in and around the cities prevented the research staff from freely moving from one place to the other to

meet the subjects; even the patients themselves were sometimes unable to reach their clinics to conduct the interview, as a result, many interviews were either canceled or postponed.

Another constraint came from the lack of comprehensive statistics regarding the prevalence, incidence, and mortality rates in each camp or city. There was only general and fragmented statistics regarding diabetes in Gaza strip. This problem led the researcher and his assistants to manually count the files of the diabetic cases in the clinics in order to estimate the number of diabetic cases. Moreover, another thing, which adds more ambiguity to the statistics of diabetes, is that many diabetic patients go to make follow-up care to both UNRWA and MOH clinics, which sometimes leads to over-reporting of the cases. Also, recruiting subjects for the second control group (non-diabetic refugees) was not an easy mission; in order to select a comparable, sex- and age-matched control group of the non-diabetic refugees, the researcher planned to select them from the neighborhoods of the cases. This process was time- and effort-consuming, because for about every three contacts, only one contact succeeded. In addition, the Palestinian community is a very conservative one, it was not easy for the research team members to be allowed to make home visits for the subjects especially the females; many of them either were reluctant or refused to be interviewed by male interviewers.

## **7.9 Quantitative Data analysis**

Quantitative data and calculations were assessed using Statistical Package of Social Sciences (SPSS) system (Diehl, 2002; DeMuth, 1999; Argyrous, 2000). Descriptive statistics and frequency distributions were generated to make comparisons among the demographic variables and the health profile of the case group and the two control groups. Cross-tabulations were used to compare between the QOL items of the WHOQOL-BREF questionnaire among the case group and the other two control groups. The analysis of variance (ANOVA or F-test) was used to evaluate the differences in the four domains of the quality of life among the different groups. In case of the presence of significant differences in the QOL domains among the groups and the independent variable composed of more than one level, a procedures called "post-hoc multiple comparisons" especially "Scheffe post-hoc" was used to allocate these differences.

**The ANOVA or F-test** represents a variety of techniques used to identify and measure source of variations within a collection of observations, hence the name analysis of variance. The one-way ANOVA is an expansion of the t-test to measure the effect of more than two levels of the discrete independent variables on one or more levels of the dependent variables. In this study, the

ANOVA and Post Hoc Multiple Comparisons were used to examine and compare the effects of several demographic and health factors on the four domains of the quality of life of the diabetic refugees, non-diabetic refugees and diabetic non-refugees in Gaza strip. The reason why the researcher preferred using ANOVA to multiple t-test because the risk of making a type I error for the series of t-tests will be greater than the stated alpha level for each t-test. Thus if the alpha level for each individual t-test is 0.05, the chance of making a type I error for all the t-test that can be conducted for a given (k) number of samples will be greater than 0.05. The ANOVA test, on the other hand, has a stated alpha level (e.g., 0.05) equal to the risk of making a type I error and this level remains always constant regardless of the number of the comparisons. ANOVA or F-ratio compares the amount of variation between the samples, called sum of squares between (SSB) and the amount of variation within, called sum of squares within (SSW). The F-ratio is a ratio of the two variances, the SSB and the SSW:  $F = \text{SSB} / \text{SSW}$ . The critical F-value is associated with two separate degrees of freedom. The degree of freedom for the estimate of the variance between samples which is the number of samples minus one, and appears in the numerator of the F-ratio:  $dfb = k - 1$ ; and the degree of freedom for the estimate of the variance within samples which is the total number of cases minus the number of samples, and appears in the denominator of the F-ratio:  $dfw = n - k$ . Then the null hypothesis is rejected if the sample value for F is greater than the critical value:  $\text{Reject } H_0 \text{ if } F_{\text{sample}} > F_{\text{critical}}$ .

Unfortunately, in case of rejecting the null hypothesis, the ANOVA or F-test does not tell us which of the samples, and how many, differ. To determine which samples are significantly different, after having performed an F-test and rejected the null, we turn to a set of techniques called Post Hoc comparisons to determine exactly which of the samples and to what extent differ(s) from the other. Unfortunately, there is little agreement within the literature as to which comparison to use. But, the researcher in this study decided to use the Scheffe post hoc comparison in the course of explaining the SPSS ANOVA procedure, because it is the most conservative test; namely, the one that is least likely to find a significant difference between the groups.

**Interpretation of ANOVA using SPSS:** The results of the ANOVA are presented in an ANOVA table (table 11). This table contains columns labeled "Source", "SS or Sum of Squares", "df - for degrees of freedom", "MS - for mean square", "F or F-ratio", and "p, prob, probability, sig., or sig. of F". The only columns that are critical for interpretation are the first and the last! The others

are used mainly for intermediate computational purposes. An example of an ANOVA table appears below:

**Table (11): Example of ANOVA test output**

	SS	df	MS	F	Sig.
Between groups				X	.000
Within Groups					
Total					

The row labeled "Between Groups", having a probability value associated with it, is the only one of any great importance at this time. The other rows are used mainly for computational purposes. Of all the information presented in the ANOVA table, the major interest of the researcher will most likely be focused on the value located in the "Sig" Column. If the number (or numbers) found in this column is (are) less than the critical value ( $\alpha$ ) set by the researcher, then the effect is said to be significant. Since this value is usually set at .05, any value less than this will result in significant effects, while any value greater than this value will result in nonsignificant effects. Here, the Sig. is printed as .000. This does not mean that the probability of obtaining F-ratio of X is zero. SPSS rounds off the probability to 3 decimal places, so that the result is read as "less than 5 in 10,000". In this study, the researcher has set the critical value ( $\alpha$ ) at 0.05, any value less than this will result in significant effects, while any value greater than this value will result in nonsignificant effects.

The ANOVA table does not tell us anything about what the effects were, just that there most likely were real effects. When the effects are significant, the means must then be examined in order to determine the nature of the effects. There are procedures called "post-hoc tests" especially "Scheffe post-hoc" to assist the researcher in this task, but often the analysis is fairly evident simply by looking at the size of the various means. The important aspect of this table is the \* next to some of the mean differences. This indicates significant differences (at the SPSS significance level of 0.05) between the means of the two samples being compared. This is verified in the column under Sig., which provides the exact significance for the differences between any two means. Where this is less than 0.05, there is also an \* next to the value in the "Mean Difference" column (Argyrous, 2000).

In order to evaluate the risk possibilities of having lower QOL scores of the diabetic refugees (the case group), the adjusted odds ratios (OR) with the 95% confidence intervals (CI) were calculated for the most essential variables of the 26-items WHOQOL questionnaire to determine the

probability of low QOL scores of the diabetic refugees related to effect of the refuge life and DM compared with the diabetic non-refugees (1<sup>st</sup> control group) and the non-diabetic refugees.

### **7.10 Qualitative data analysis**

The qualitative data were analyzed using a constant inductive method. Using this method, the focus is on the ways in which diabetic refugees clarify their situations regarding the 26 items of the WHOQOL questionnaires. According to Polit (1995), qualitative data analysis using the inductive method is a constructionist in nature: they involve putting together segments of information into a broader meaningful conceptual pattern. LoBiondo-Wood & Haber (1994) have wonderfully described this method: “It is a moving from the participant’s description to the researcher’s synthesis of all participants’ descriptions”. Munhall and Oiler (1986) reported that qualitative research requires that the researcher simultaneously collect, code and analyze the data from the first day in the field. The coding process has three levels: Level I begins with using the exact words that the participants use. Level II is the formulation of ‘categories’ result from condensing codes from level I. Level III is the creation of ‘theoretical constructs’ derived from a combination of academic and clinical knowledge.

For this study, the process of analyzing the interviews described by Munhall & Oiler (1986) and LoBiondo-Wood & Haber (1994) was used as the following:

1. The researcher has thoroughly read the entire interview transcriptions and divided the transcriptions into thought segments,
2. He specified the significant phrases in each thought segment, using the words of the participant,
3. He distilled each significant phrase to express the central meaning of the segment in the words of the researcher (Level I: formulating codes).
4. Then he performed preliminary synthesis of central meanings of all thought segments for each participant with a focus on the essence of the phenomena being studied (Level II: categorizing the data), and
5. He performed the final synthesis of the essence that has surfaced in all participants’ descriptions, resulting in creating the ‘theoretical constructs’ which are the themes that emerge for further analysis (Level III).

For this study, the general goal of the qualitative data analysis was to identify the codes and categories, and then organize them in a way that accounts for the majority of data and helps



identify recurring themes. For the purpose of summarization, the researcher has only cited some sentences or parts of sentences in chapter 8 & 9 from interview transcriptions (see appendix G). Then, he integrated the emerged themes of the qualitative approach (interviews) along with the quantitative results of the 26 items of the WHOQOL questionnaire (see Chapter 10), because the two approaches have examined and explored the same points (26 items of the Questionnaire) but from different dimensions; the quantitative approach tries to answer how many or to what extent but the qualitative approach tries to answer “Why”. This is why the researcher decided to fuse the results of two approaches together and not to specify a separate topic for the results of the interviews. This process of the integration was extensively very exhausting and time-consuming procedure, because every similar piece of information had to be coded and categorized to generate broader themes to express the feelings and the concerns of the refugees and then to be integrated with the quantitative analysis.

## **Chapter 8**

### **Results of the study (Part I)**

#### **Impact of the refuge life on the QOL of diabetic refugees**

The purpose of this exploratory comparative study is to assess the effects of the refugee status and diabetes mellitus on the quality of life of the diabetic Palestinian refugees in the refugee camps in Gaza strip. 591 subjects from different areas in Gaza strip were selected for the study and divided into three groups: the case group which composed of 197 diabetic refugees recruited from three refugee camps; the first control group composed of 197 diabetic non-refugees selected from three cities in Gaza strip; and the second control group which also composed of 197 non-diabetic refugees from the same refugee camps of the case group. The results were obtained through semi-structured interviews, filling the questionnaire and the systematic reviews of the participants' documents in the clinics.

The results of the study are presented in two chapters: chapter 8 and chapter 9. Chapter 8 focuses on the impact of the refuge life on the QOL domains among the diabetic refugees while chapter 9 highlights the effect of DM on the QOL of the same group.

The findings in this chapter are presented in six parts. The first part describes the demographic data and socio-economic status of the participants. The second section describes health profile and diabetes status of the diabetic refugees and non-refugees. These two sections are important to explore the life context of the participants to understand their perceptions about the quality of life and management of their illness. The third section measures the effect of the refuge life on the quality of life of the diabetic refugees by comparing the differences in the WHOQOL items among the case and the 1<sup>st</sup> control group using SPSS crosstabulations. Part four analyzes the variances of quality of life domains among the diabetic refugees (the case group) and the diabetic non-refugees (the first control group).

The fifth section compares between the health services provided by the Palestinian Ministry of Health (PMOH) and by UNRWA for the diabetic patients in Gaza Strip as perceived by the diabetic patients themselves. The results of this section are very important for improving the provision of the health care of diabetes. The last part discusses the impacts of diabetes-related complications on the QOL domains which, according to several studies, the most independent factor which negatively affected the HRQOL.

## 8.1 Demographic data and socio-economic status of the participants

This part presented several characteristics of the participants such as gender, age, level of education, marital status, living place, type of the houses, occupation, monthly income, and the number of persons financially dependent on the participant. These characteristics are very crucial to understand the refugees' perceptions about their quality of life and management of their illness.

### 8.1.1 Distribution of the case group and 1<sup>st</sup> control group by gender

According to table (12), the participants in each group composed of 53% males and 47% females. These percentages are consistent in the case group and control groups in order to minimize the selection bias.

**Table (12): Distribution of the case group and 1<sup>st</sup> control group by gender**

			Gender		Total
			Male	Female	
Group	Diabetic Refugees	Count	104	93	197
		Percent	52,8%	47,2%	100,0%
	Diabetic Non-refugees	Count	104	93	197
		Percent	52,8%	47,2%	100,0%
Total		Count	208	186	394
		Percent	52,8%	47,2%	100,0%

### 8.1.2 Distribution of the case group and 1<sup>st</sup> control group by age

Table (13) shows that 33% of the subjects among the case and the control groups were between the ages of (50-60) years, 25% above 60 years, 11% between the ages of (30-39) years, while 6% less than 30 years old.

**Table (13): Distribution of the case group and 1<sup>st</sup> control group by age**

			Age					Total
			Less than 30	30-39 years	40-49 years	50-60 years	More than 60	
Group	Diabetic Refugees	Count	12	21	49	66	49	197
		Percent	6,1%	10,7%	24,9%	33,5%	24,9%	100,0%
	Diabetic Non-refugees	Count	12	21	49	66	49	197
		Percent	6,1%	10,7%	24,9%	33,5%	24,9%	100,0%
Total		Count	24	42	98	132	98	394
		Percent	6,1%	10,7%	24,9%	33,5%	24,9%	100,0%

### 8.1.3 Distribution of the case group and 1<sup>st</sup> control group by the level of education

The educational attainment of the participants ranged from illiteracy (they did not receive any formal education) to higher educational level (table 14).

Among the case group (diabetic refugees), 28% had no formal school education and are assumed to be illiterate, 15% had only primary school education. About 36% of them had secondary and tertiary school education and 21% had higher education. Among the control group (diabetic non-refugees), only 3% had no formal school education, while 38% had tertiary school education and 47% were able to attain higher education. These ratios reflect the huge gap in the educational rates among the refugees in the camps and the non-refugees in the cities, which may be related to the availability of the educational and financial resources.

**Table (14): Distribution of the case group and 1<sup>st</sup> control group by level of education**

			Level of education					Total
			None at all	Primary School	Secondary School	Tertiary School	Higher education	
Group	Diabetic Refugees	Count	56	29	30	40	42	197
		Percent	28,4%	14,7%	15,2%	20,3%	21,3%	100,0%
	Diabetic Non-refugees	Count	5	10	13	75	94	197
		Percent	2,5%	5,1%	6,6%	38,1%	47,7%	100,0%
Total		Count	61	39	43	115	136	394
		Percent	15,5%	9,9%	10,9%	29,2%	34,5%	100,0%

### 8.1.4 Distribution of the case group and 1<sup>st</sup> control group by marital status

Table (15) indicated that most of the participants in the case group (76%) were married, about 15% were widowed, and 7% were single or never married at the time of the interview. Most of the single women reported that diabetes was the major barrier for them to get married. However, most of the married women they married before they got diabetes.

**Table (15): Distribution of the case group and 1<sup>st</sup> control group by marital status**

			Marital status				Total
			Single	Married	Widowed	Divorced	
Group	Diabetic Refugees	Count	14	151	29	3	197
		Percent	7,1%	76,6%	14,7%	1,5%	100,0%
	Diabetic Non-refugees	Count	19	163	15	-	197
		Percent	9,6%	82,7%	7,6%	-	100,0%
Total		Count	33	314	44	3	394
		Percent	8,4%	79,7%	11,2%	,8%	100,0%

### 8.1.5 Distribution of the case group and 1<sup>st</sup> control group by house type

This variable is considered a significant indication for the economic status of the participants especially the refugees. As shown in table (16), about 25% of the refugees still live in houses built for them by UNRWA since their displacement in 1948 as the first shelter, while the other 70% live in their own houses. However, these houses are still compacted with each other and lack the basic infrastructure such as roads and sewers. On the other side, 96% of the non-refugees had own houses and only 4% lived in rented houses.

**Table (16): Distribution of the case group and 1<sup>st</sup> control group by house type**

			House type			Total
			Own	UNRWA	Rent	
Group	Diabetic Refugees	Count	137	50	10	197
		Percent	69,5%	25,4%	5,1%	100,0%
	Diabetic Non-refugees	Count	190	-	7	197
		Percent	96,4%	-	3,6%	100,0%
Total		Count	327	50	17	394
		Percent	83,0%	12,7%	4,3%	100,0%

### 8.1.6 Distribution of the case group and 1<sup>st</sup> control group by the occupation

Table (17) shows that the majority of the diabetic refugees (59%) were unemployed, in comparison with 39% among the diabetic non-refugees. About 40% of the refugees work in temporary jobs and gain approximately 200 US\$ or less, as indicated by the following section (8.1.7).

**Table (17): Distribution of the case group and 1<sup>st</sup> control group by occupation**

			Occupation		Total
			Employed	Unemployed	
Group	Diabetic Refugees	Count	80	117	197
		Percent	40,6%	59,4%	100,0%
	Diabetic Non-refugees	Count	120	77	197
		Percent	60,9%	39,1%	100,0%
Total		Count	200	194	394
		Percent	50,8%	49,2%	100,0%

### 8.1.7 Distribution of the case group and 1<sup>st</sup> control group by the income status

Due to the current unstable situation in Gaza, it was difficult to obtain an accurate estimate of a fixed monthly income for the participants. The source of income varied from no regular source to multiple sources for small amounts. Moreover, most of the women depended on their husbands or sons for life expenses. As indicated in table (18), the reported monthly income of the diabetic refugees ranged from no income to more than 500 US\$. The majority of them (65%) had a monthly income less than 200 US\$, in comparison with only 31% of the non-refugees. While 25% of the diabetic refugees had an average income 200-500 US\$, 43% of the non-refugees reported the same monthly income. Approximately, 10% of the diabetic refugees had monthly income more than 500 US\$ while 26% of the non-refugees receive the same amount.

**Table (18): Distribution of the case group and 1<sup>st</sup> control group by income status**

			Income status			Total
			Below 200 US\$ *	200-500 US\$*	More than 500 US\$*	
Group	Diabetic Refugees	Count	129	49	19	197
		Percent	65,5%	24,9%	9,6%	100,0%
	Diabetic Non-refugees	Count	61	84	52	197
		Percent	31,0%	42,6%	26,4%	100,0%
Total		Count	190	133	71	394
		Percent	48,2%	33,8%	18,0%	100,0%

\* 100 USD  $\cong$  82 EURO  $\cong$  450 Israel New Shekels (ILS) (mid-market rate as of 27.7.2005)

### 8.1.8 Distribution of the case group and 1<sup>st</sup> control group by the number of persons financially dependent on him/her

The results in table (19) showed that 59% of the case group had to financially support 0-5 members of their families or relatives, 38% support 6-10 persons and 3% supported more than 10 persons. In contrast, 74% of the control group (diabetic non-refugees) had to financially support 0-5 members of their families, 21% support 6-10 persons, and only 5% support more than 10 persons.

**Table (19): Distribution of the case group and 1<sup>st</sup> control group by number of persons financially dependent on the subject**

			Nr. of persons financially dependent on you			Total
			0-5	6-10	More than 10	
Group	Diabetic Refugees	Count	116	75	6	197
		Percent	58,9%	38,1%	3,0%	100,0%
	Diabetic Non-refugees	Count	145	41	11	197
		Percent	73,6%	20,8%	5,6%	100,0%
Total		Count	261	116	17	394
		Percent	66,2%	29,4%	4,3%	100,0%

## 8.2 Health profile and diabetes status of the case and 1<sup>st</sup> control group

The following section presents the diabetic statistics of the study population. 349 participants (the case group and the first control group) in the study had diabetes which had been confirmed by a physician, and all of them were under medical follow-up.

### 8.2.1 Distribution of the case group and 1<sup>st</sup> control group by the duration of diabetes

According to table (20), the duration or length of time since the initial diagnosis ranged from 1 year to more than 10 years. About 34% of the diabetic refugees had been diagnosed with diabetes for more than 10 years and about 30% had the diagnosis of diabetes for 6-10 years. About 28% had been diagnosed for 2-5 years and 8% for one year. In contrast, about 14% of the non-refugees had diabetes for more than 10 years, 43% for 6-10 years, and 5% for one year.

**Table (20): Distribution of the case group and 1<sup>st</sup> control group by duration of diabetes**

			The first time to know that you have diabetes				Total
			One year ago	2-5 years ago	6-10 years ago	More than 10 years ago	
Group	Diabetic Refugees	Count	15	56	60	66	197
		Percent	7,6%	28,4%	30,5%	33,5%	100,0%
	Diabetic Non-refugees	Count	9	74	84	30	197
		Percent	4,6%	37,6%	42,6%	15,2%	100,0%
Total		Count	24	130	144	96	394
		Percent	6,1%	33,0%	36,5%	24,4%	100,0%

### 8.2.2 Distribution of the case group and 1<sup>st</sup> control group by type of diabetes

Table (21) shows that 8% of the population had Type 1 diabetes and 92% had Type 2 diabetes.

**Table (21): Distribution of the case group and 1<sup>st</sup> control group by type of diabetes**

			Type of Diabetes		Total
			Type 1	Type 2	
Group	Diabetic Refugees	Count	15	182	197
		Percent	7,6%	92,4%	100,0%
	Diabetic Non-refugees	Count	15	182	197
		Percent	7,6%	92,4%	100,0%
Total		Count	30	364	394

### 8.2.3 Distribution of the case group and 1<sup>st</sup> control group by the type of treatment

Table (22) shows different types of treatments: about 24% of the diabetic refugees were on insulin therapy compared with 11% of the non-refugees, about 54% of the diabetic refugees and 52% of the diabetic non-refugees were on oral hypoglycemic agents (OHAs), about 15% of the diabetic refugees were on combination of insulin and OHAs compared with 26% of the non-refugees, and only 7% of the refugees were on dietary management.



**Table (22): Distribution of the case group and 1<sup>st</sup> control group by type of treatment**

			Medication for diabetes				Total
			Pills	Insulin	Pills and Insulin	Diet	
Group	Diabetic Refugees	Count	106	47	30	14	197
		Percent	53,8%	23,9%	15,2%	7,1%	100,0%
	Diabetic Non-refugees	Count	103	21	52	21	197
		Percent	52,3%	10,7%	26,4%	10,7%	100,0%
Total		Count	209	68	82	35	394
		Percent	53,0%	17,3%	20,8%	8,9%	100,0%

#### 8.2.4 Distribution of the case group and 1<sup>st</sup> control group by the diabetic complications

As shown in table (23), the percentages of refugees with complications of diabetes is very high (80%) in comparison with non-refugees (29%). Interestingly, more than 32% of the refugees reported having more than one complication and only 20% did not have any complication. In contrast, only 5% of the non-refugees reported having more than one complication and 71% had no complications. The most common complications reported by the case group were retinopathy (20 %).

**Table (23): Distribution of the case group and 1<sup>st</sup> control group by diabetic complication**

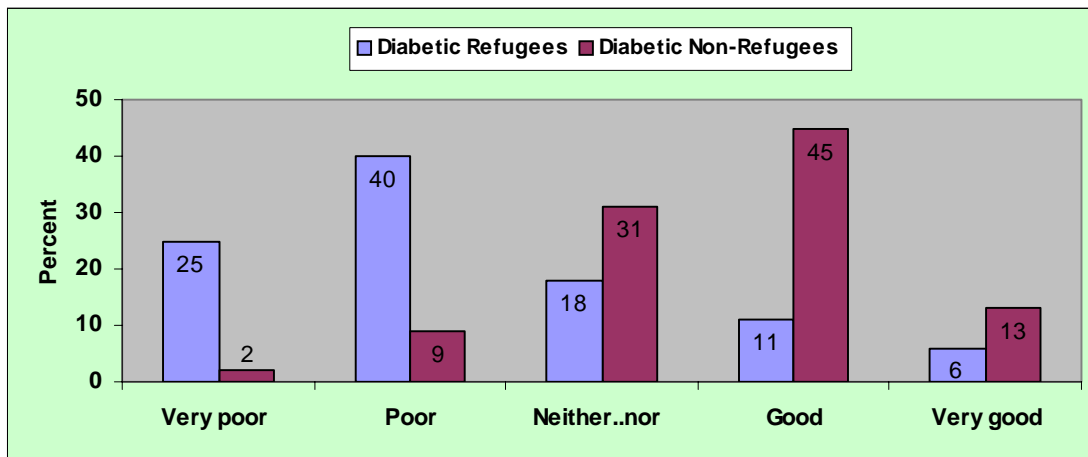
			Complications of Diabetes					Total	
			Retino-pathy	Nephro-pathy	Neuro-pathy	Diabetic foot	Nothing		More than one complication
Group	Diabetic Refugees	Count	39	12	17	26	39	64	197
		Percent	19,8%	6,1%	8,6%	13,2%	19,8%	32,5%	100,0%
	Diabetic Non-refugees	Count	16	14	10	8	139	10	197
		Percent	8,1%	7,1%	5,1%	4,1%	70,6%	5,1%	100,0%
Total		Count	55	26	27	34	178	74	394
		Percent	14,0%	6,6%	6,9%	8,6%	45,2%	18,8%	100,0%

### 8.3 Measuring the effect of the refuge life on the quality of life of the diabetic refugees by crosstabulations

This section assesses the effect of the refuge life on the quality of life of the diabetic refugees in Gaza strip by comparing their QOL items with the 1<sup>st</sup> control group of diabetic non-refugees. Both groups were matched for age, sex and having only a history of diabetes.

### 8.3.1 Rating quality of life

Both groups were asked to rate their QOL on a scale from very poor to very good. The results were amazing (figure 4): 65% of the case group reported poor and very poor QOL compared with 11% of the control group. In the case group, about 17% had rated their QOL as good and very good, meanwhile about 58% among the control group did so.



**Figure (4): How would you rate your quality of life?**

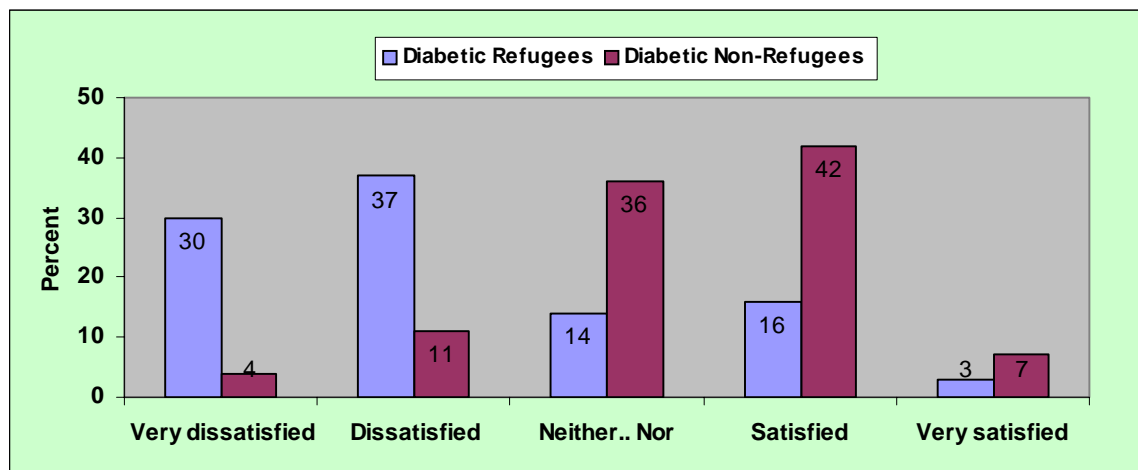
A 55 years old diabetic refugee described his life in the camps: “My quality of life is very poor, I still live in an extended family house, I don’t have a good job, I don’t have enough money to support my family, even the medication, sometimes I can not buy them”. He continued: “The life as a refugee in the camp is very hard, the houses are stick to each other, we don’t have good clinics or hospitals, we can not easily traveled to the hospitals in Gaza because of the checkpoints near Natzarim settlement, sometimes I had to walk 4-5 kilometers to avoid the checkpoint and because of the strict seize around the camp”.

Regarding diabetes: he continued: “The diabetes has worsened my life and added another overload. Honestly, it is not easy for me to keep eating diabetic diet; sometimes I am invited to a wedding parties in which normal lunch (rice, meat, and sweets) are served. This situation creates a conflict for me because I know that I have to carry out social roles and to share the others in eating and at the same time I have to comply with the therapeutic diet. This is a small example how diabetes negatively affected my life”. “And not forget that Sugar Disease (he means diabetes) can causes problems in the kidneys, eyes and the nerves; and now I have already a small infection in my link foot”.

### 8.3.2 Satisfaction with health

The case and control subjects were asked to rate their satisfaction with their health on a scale from very dissatisfied to very satisfied. According to figure (5), More than two thirds of the cases were dissatisfied and very dissatisfied with their health, while less than 15% of the controls were

so. On the other hand, about 19% of the diabetic refugees were satisfied and very satisfied in comparison with about 49% of the non-refugees.



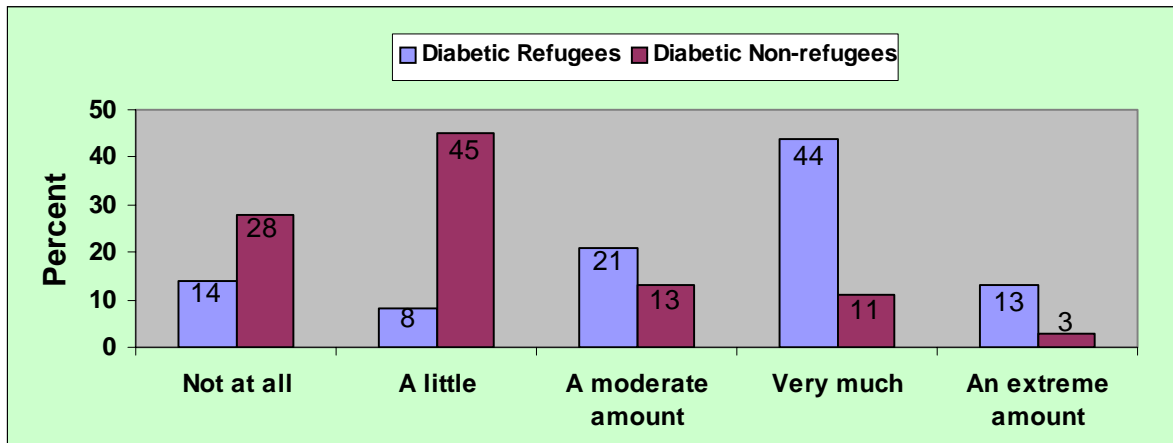
**Figure (5): How satisfied are you with your health?**

He continued: “I am not satisfied with my health at all because I don’t know what will happen to me in the next years, also sometimes I do not know what to do more to control the sugar. Even the UNRWA clinic in the camp does not provide a good care, it is always full and I have to wait several hours to see the doctor for five or ten minutes and I can not measure my sugar at home because I do not have “glucometer”. And it is very expensive to go to a private doctor. Now I have an infection in my big toe and I don not have enough money to buy the compresses, the gauzes and the ointment”.

A 60 years old refugee man suffering from retinopathy said: “My health is poor and I feel that it becomes worse and worse. I can not see well and may be I will become blind because of diabetes. I try my best to control my blood sugar, but it seems that it is not easy”.

### 8.3.3 Physical pain

The patients were asked to rate “to what extent do you feel that physical pain prevents you from doing what you want?” on a scale from not at all to an extreme amount. Diabetes is considered one of the most physiologically demanding of the chronic medical illnesses, because it causes serious complications such as cardiovascular disease, retinopathy, end-stage renal disease, and amputation. As indicated in figure (6): more than 57% of the refugees reported that physical pain prevented them from performing their needs very much to extreme amount while about 14% of the diabetic non-refugees reported so.

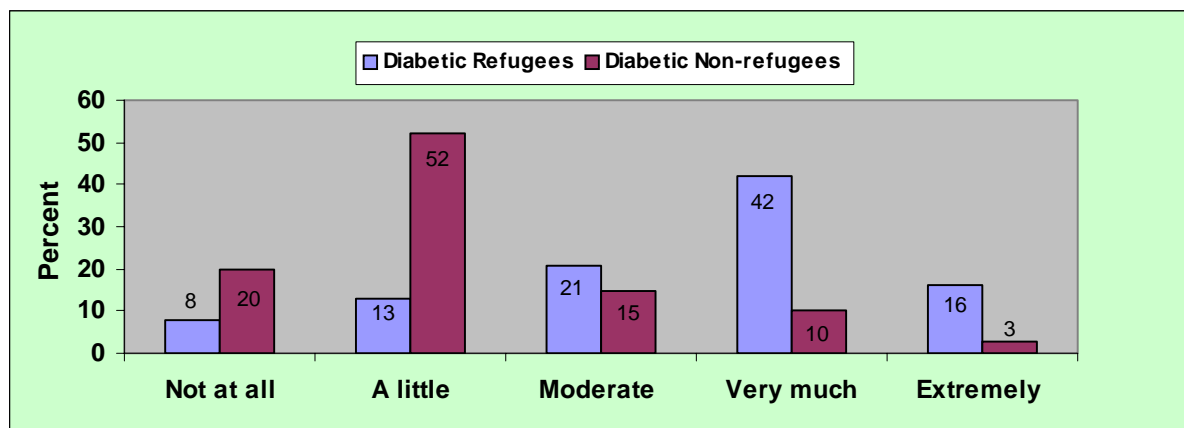


**Figure (6): To what extent do you feel that physical pain prevents you from doing what you need to do?**

### 8.3.4 Medical treatment to function in daily life

The case and control groups were asked to answer the question “How much do you need any medical treatment to function in your daily life?” on a scale from not at all to extreme amount.

About 58% of the case group reported that they need medical treatment “very much and to extreme amount” in order to be able to function in their daily lives, meanwhile only 13% of the control group reported the same results. Only 8% of the refugees said that they manage diabetes with diet and weight reduction in comparison with 20% of the non-refugees (figure 7).



**Figure (7): How much do you need any medical treatment to function in your daily life?**

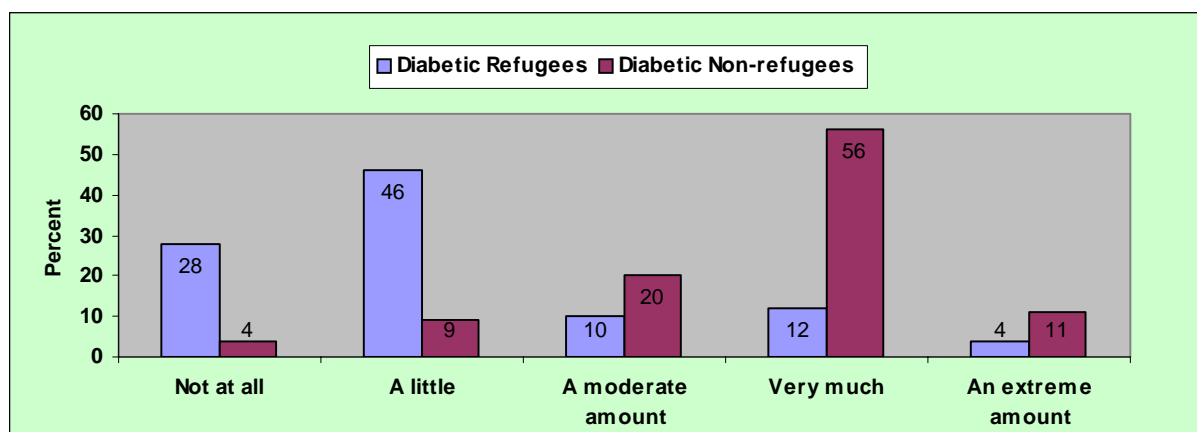
40 years old IDDM woman said: “The doctor has prescribed for insulin injection for my diabetes, but the problem for me that this drug is not always available in the UNRWA Clinic and sometimes I could not buy it because we do not have enough money because

my husband is not working. Sometimes for three or four days I do not take any insulin and this makes me very sick”.

A diabetic refugee man suffering from diabetic foot said: “I need every day about 24-36 insulin units for my (Sugar), this depends on the level of sugar in the blood but the problem for me is that I do not measure my blood sugar because I do not have the equipment to do this, instead, I guess my self and I inject myself based on my guess. Many times, I forget or not willing to take the medication”.

### 8.3.5 Enjoying life

The patients were asked to rate “How much do you enjoy life?” on a scale from not at all to an extreme amount. As shown in figure (8), more than 74% of the diabetic refugees answered this question by “a little and not at all”, in comparison with only 13% of the control group. On the other hand, about 67% of the diabetic non-refugees said that they enjoy their life, and 33% of them still reported that they did not enjoy life.



**Figure (8): How much do you enjoy life?**

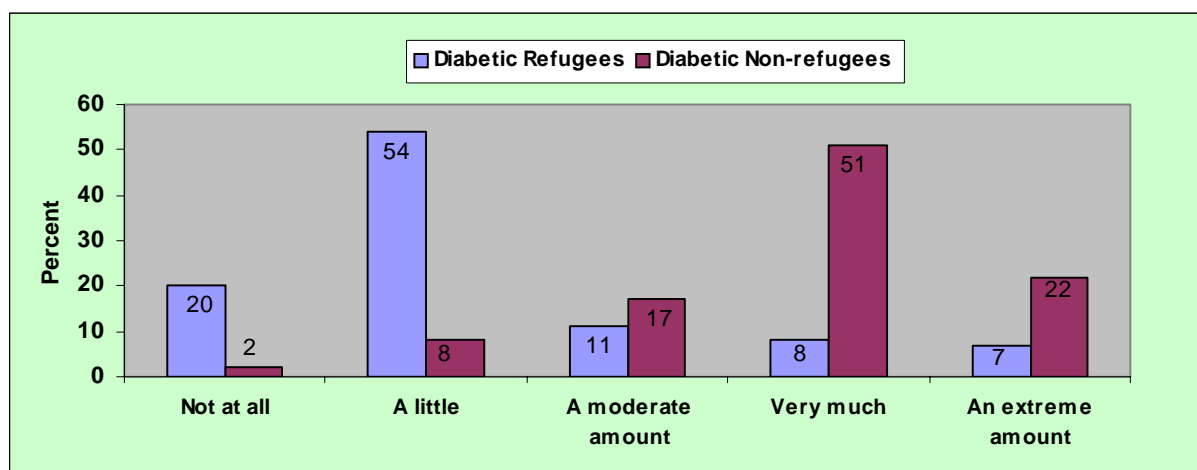
A diabetic refugee answered this question: “How can I enjoy my life and I suffer from diabetes. Actually, I am always worried that I will die earlier because diabetes is a life-long disease and very difficult to control. Now I have diabetic foot, who knows which complications will appear in the future. I know many diabetic patients in the camps sitting on wheelchairs and I know others who died early”.

“We, as refugees living in the camps, there is no chance for us to enjoy life. We are not allowed to leave Gaza strip to other countries even for medical purposes, and sometimes we are not allowed to leave this camp under a security rationalizations, and in case you are allowed to freely travel, you do not have enough money to do so...The only thing which alleviate our suffering is our faith in God, that all of these suffering that we are going through is considered as an exam for us in this life and if we afford this we will take our prize in the day after”.

A 35 years old diabetic refugee woman suffering from diabetes for 17 years said: “To enjoy life you need to be healthy, to have money and to be perceived by your society as a good person. For me the life is miserable, till now I did not get married! Do you know why? Simply because I have diabetes and the people pointed to me (this is the pitiful woman). People let me always feel that I am sick and I need their mercy and tenderness” Mostly, I stay at home to avoid such feelings”

### 8.3.6 To what extent do you feel your life to be meaningful?

The responses of the case and control groups for this question were rated on a scale from not at all to an extreme amount. Figure (9) shows that about 74% of the diabetic refugees reported that life has a little meaning or meaningless, while about 73% of the diabetic non-refugees felt that their life is meaningful very much or to an extreme amount. However, there are another 26% of the diabetic refugees who still feel that their life is meaningful moderately to an extreme amount.



**Figure (9): To what extent do you feel your life to be meaningful?**

A 42 woman said that: “To have diabetes and to live in a refugee camp is a very catastrophic situation. I have 6 children and we live in a 3-room house built by UNRWA. In the camp there is no any place to go to spend a good time”

Another refugee man said: “In my life, there is nothing to let me think that the life has a meaning. Every thing around remind me with the poverty and hopelessness. My health, my economic situation, and the daily suffering which we experience in our lives made it very difficult to find any meaning for the life. I feel myself different from the others because I have to follow strict diet, sometimes I feel dizzy while sitting with people because of the sugar problems which frustrate me”. However, there is only one thing which gives me a ray of hope, namely, my religious values and faith in God, which necessitate that the person must always be satisfied with the disease and with his life conditions. I perceive my disease and my hard life as an exam from God, and I am satisfied with God’s will”.

### 8.3.7 How well are you able to concentrate?

The responses the participants gave about their ability to concentrate were rated on a scale from not at all to extremely. The ability to concentrate depends on several factors such as the state of health, presence of complications, number of taken medications and its adverse effects, and the living conditions around with its associated stressors. Because the diabetic refugees experience most of the previous factors, figure (10) showed that about 10% of them reported that they are unable to concentrate at all; more than 43% of them stated that their ability to concentrate is very little; and approximately 27% said that they were able to concentrate moderately. On the other hand, 70% of the control group were able to concentrate very much or extremely.

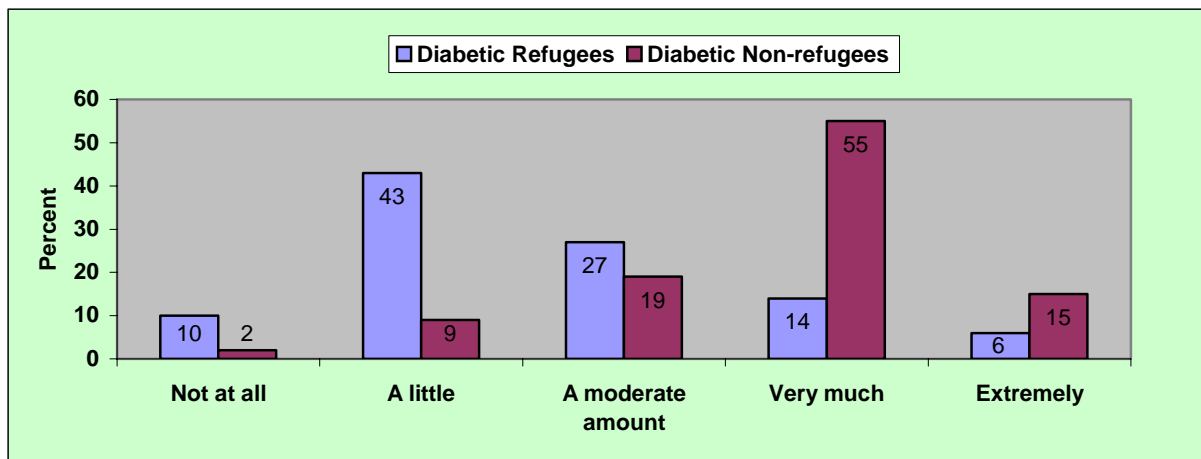
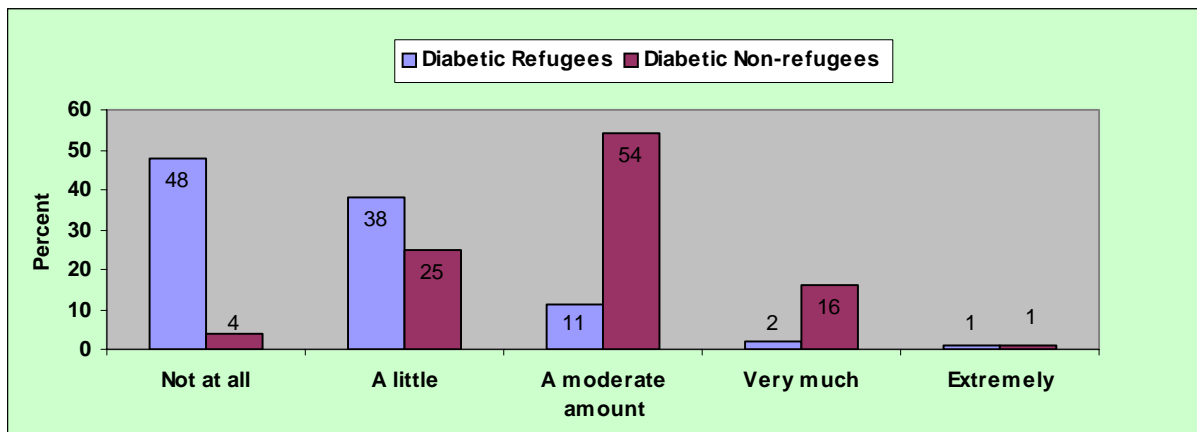


Figure (10): How well are you able to concentrate?

### 8.3.8 How safe do you feel in your daily life?

The answers of the cases and controls to this question were rated on a scale from not at all to extremely. As shown in figure (11), only about 3% of the refugees and 17% of the non-refugees felt safe in their daily life. In contrary, about 86% of the refugees reported no or little safety in their life and about 79% of the non-refugees felt little to moderately safe in their daily life.



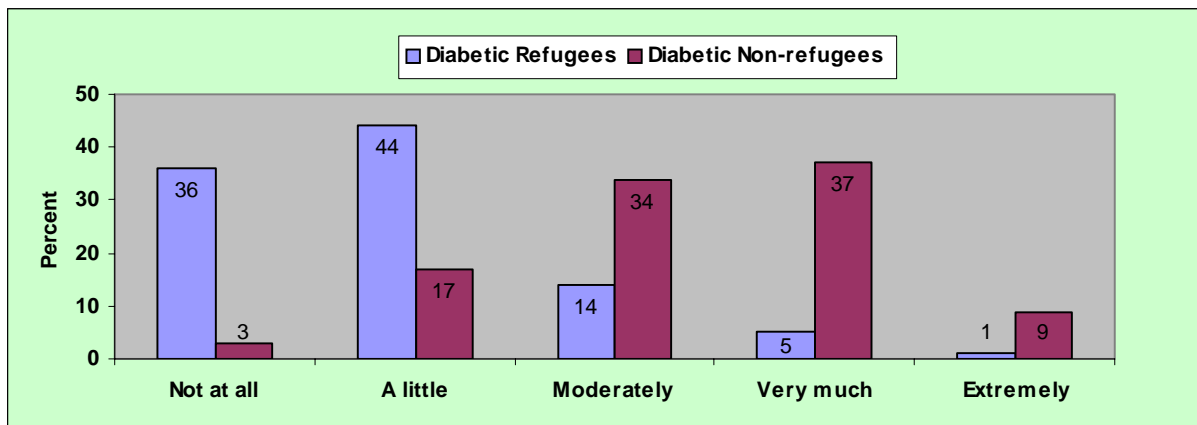
**Figure (11): How safe do you feel in your daily life?**

The 55 years old diabetic man answered while laughing: “What type of safety you are talking about..!! Day and night we hear the voices of the guns and the Helicopters bombardment. We don’t feel safe even when we sit at our homes. Many times the Apache Helicopters has attacked with missiles a civilized and innocent people in the middle of the camp in order to kill a (wanted) person. You remember before two years exactly before Ramadan Aid (Fasting fest) when the Helicopters killed 15 innocent persons in Annusirat camp including children and the Doctor of the MOH clinic in the camp and after that “they” apologized saying that it was a technical failure. If you want to go Khan Yunis city or Rafah which they are only 15 Kilometers away, you need at least 4-6 hours (when you are lucky) because of the checkpoints and the Israeli strict control measures. And very often you are not allowed to pass. Approximately, in every Palestinian house, there is a wounded person, a martyr or a prisoner. All of these stressors increase my sugar and I am not able to concentrate to take my medications or to regulate my diet.”

### 8.3.9 How healthy is your physical environment?

The patients were asked to rate “how healthy is their environment” on a scale from not at all to extremely. According to the results shown in figure (12), 36% of the diabetic refugees have rated their environment as unhealthy at all compared with only 3% of the city inhabitants. 44% of the refugees considered their physical environment a little bit healthy in comparison with only 27% of the non-refugees. On the other hand, about 46% of the non-refugees felt that their environment is healthy while only 6% of the refugees felt so.





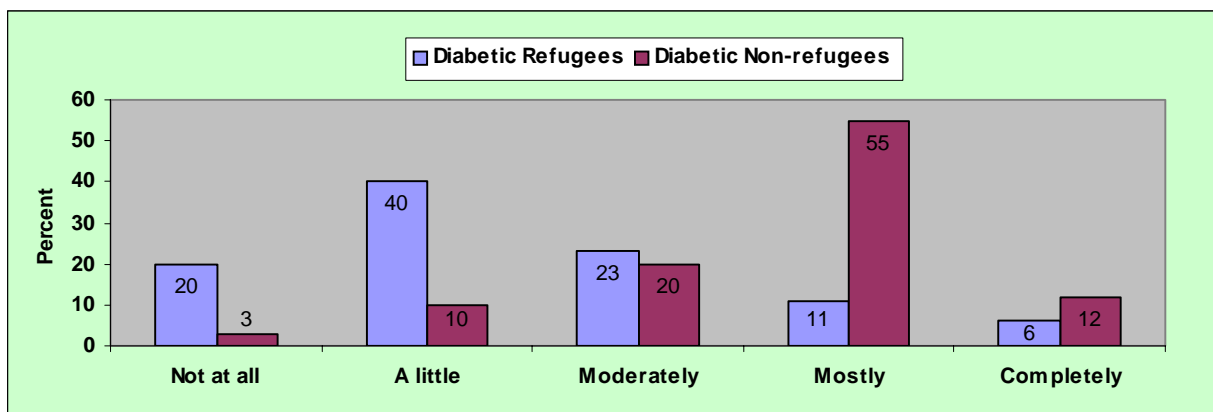
**Figure (12): How healthy is your physical environment?**

A 60 years old refugee man has amputated leg and sits on a wheelchair said: “Since our exodus I live in an UNRWA house which lacks good ventilation, healthy sewage system, and it is compacted with other houses. I always ask for help to go to bathroom or to take a shower because I can not buy the appropriate equipments to help me moving at home on my wheelchair”

A 63 years old diabetic refugee woman said: “Our environment is very bad. The streets are not clean, the water is not fresh. There is no good health care for us in the clinics. In addition to the stress we have from the occupation, all of these thing lead worsening of the disease”.

### 8.3.10 Do you have enough energy for every day life?

The responses of this question were rated on a scale from not at all to completely. Figure (13) shows that approximately 60% of the diabetic refugees reported that they either did not have energy at all or only a little amount for every day life; meanwhile, only 13% of the diabetic non-refugees did so. In contrary, 67% of the non-refugees had mostly and completely enough energy to normally function in their daily life in comparison with only 16% of the case group.



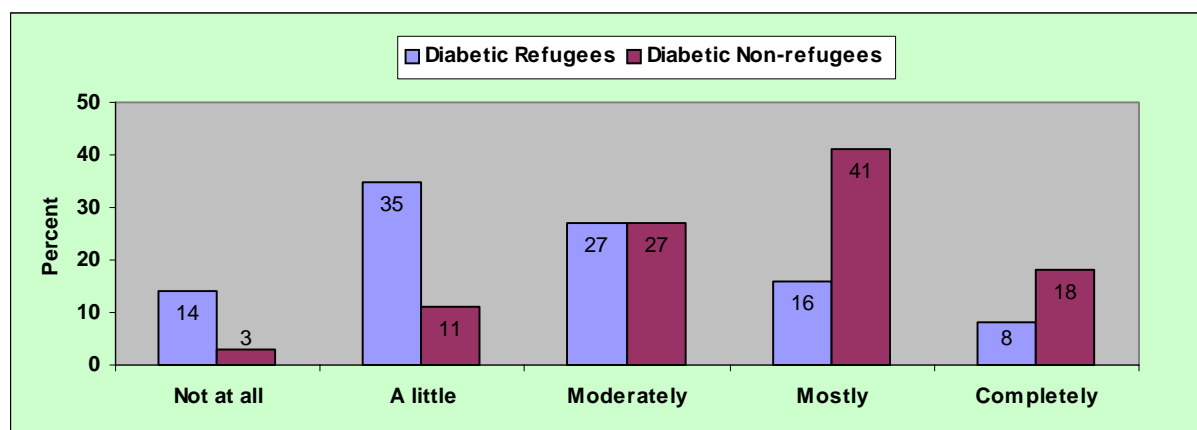
**Figure (13): Do you have enough energy for everyday life?**

A 49 years old woman said: “since I got the diabetes, I feel my self very lazy and sometimes I don’t have any motivation to do any thing even for my children. My sugar is mostly either is high or low and in both cases I feel tired”.

A diabetic refugee man said: “Sometimes when my (sugar) is normal I feel my self very healthy and full-energetic, and sometimes when my sugar is low or high related to stress I feel myself very tired and sometimes depressed. But, since the appearance of the infection in my foot (he means the diabetic foot), I tried not to move too much in order not to worsen the wound. This, in turn, let me feel depressed”.

### 8.3.11 Are you able to accept your bodily appearance?

The case and control groups had rated their acceptance to their bodily appearance on a scale from not at all to completely. As indicated in figure (14), about 49% of the diabetic refugees had not accepted their bodily appearance at all or a little compared with 14% of the non-refugees. But still there are a relatively large number of the refugees (24%) who accepted their body appearance in spite of the complications.



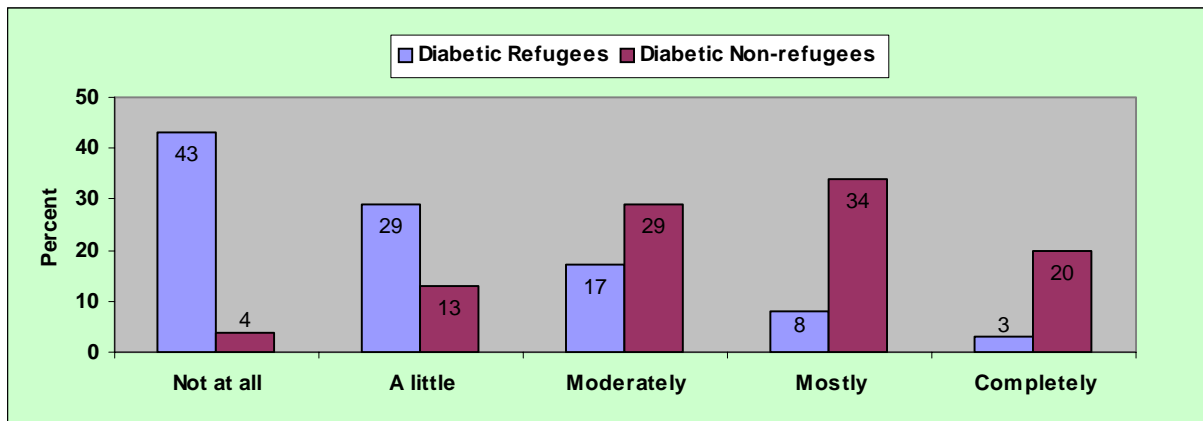
**Figure (14): Are you able to accept your bodily appearance?**

A 32 married woman said: “I have diabetes since 12 years I take insulin to treat it. I became very thin, my skin appear very bad because of the every-day injection. My husband tries always to support me and to reassure me, but I know that it is very difficult for him. Sometimes I do not take the injection in order to improve the appearance of skin”

The 55 years old diabetic refugee said “Before the complication, every thing was normal for me and I perceived my body image as normal but after the appearance of the infection in my foot I was not able to walk normally and I go lamely (little claudication). In addition, the sites of insulin injection in my abdomen and legs distorted the appearance of the skin. Accordingly, I can not wear short trousers. However, I tried always to persuade my self and to perceive all of these problems as an exam from God and I have to pass this exam in return for the reward in the other life.”

### 8.3.12 Have you enough money to meet your needs?

The responses to this question were rated on a scale from not at all to completely. As shown in figure (15), more than 43% of the refugees reported not having money at all, about 29% of them had a little money and about 17% had moderately enough money to meet their needs, while only 11% had enough money to support their needs. On the other hand, 54% of the non-refugees reported having enough money to meet their needs.

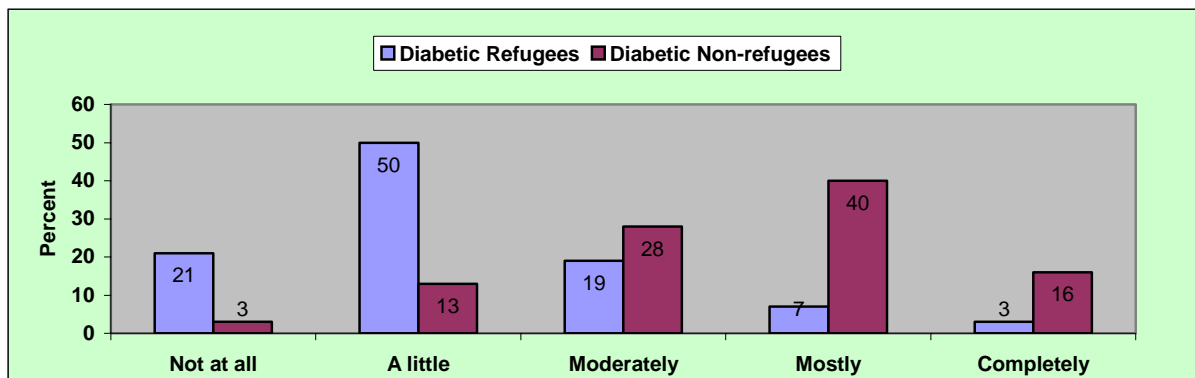


**Figure (15): Have you enough money to meet your needs?**

55 years old diabetic refugee said: “Before 1995 I was working in Israel in the construction (as a builder) and I have earned enough money, but after that and suddenly the Israeli have cancelled my permission (along with many workers) to enter Israel. Since that time, I am trying to find a durable job but without success. Sometimes I work 3-4 months and sometimes I do not find any job for 6 months. The best monthly income I have ever gained since 1995 was 2500 INS (about 550 USD) and this was only for a short-term job. Now I have 5 children and I have to support them financially in addition to my mother who lives with me at the same house. Sometimes I receive some irregular aids from charitable institutions and associations but these aids are not enough. Very often, I have lost good work offer in other cities like Rafah or Khan Yunis in the south because I can’t reach such areas because of the closures and “Abo Holy” checkpoints.” He added: “the situation for me has changed since I had this complication (Diabetic foot), because I can not work any more.”

### 8.3.13 How available to you is the information that you need in your day-to-day life?

The participants’ responses to this question were rated on a scale from not at all to completely. In figure (16), about 71% of the refugees stated that they could not get enough information in day-to-day life regarding their disease and its management. Most of them did not know the etiological factors of the disease and the best way to manage it. Only 10% of them said that the information is available to them in comparison with 56% of the non-refugees.

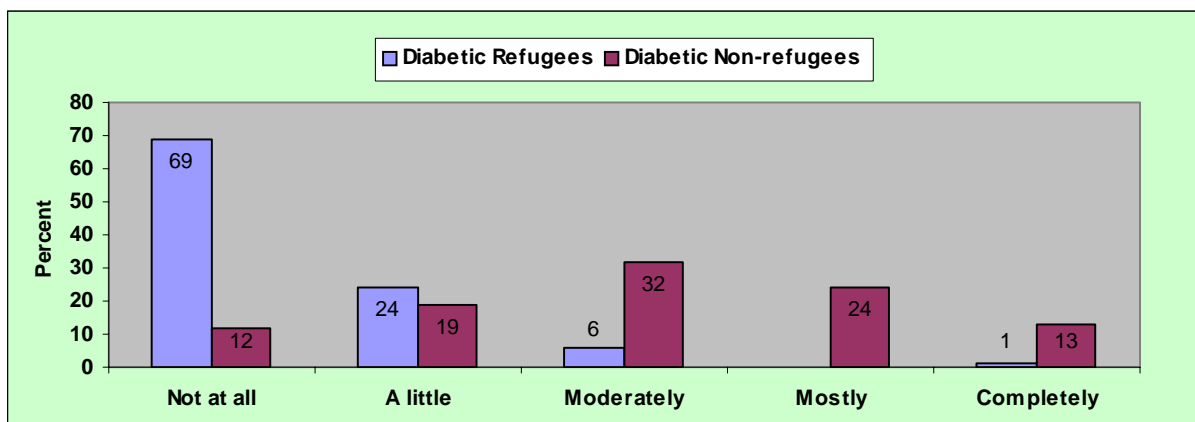


**Figure (16): How available to you is the information that you need in your day-to-day life?**

He continued “Honestly, I do not know too much about diabetes. I did not read any book or bulletins about it. I heard from other diabetic people that it causes so and so and it is controlled by insulin and pills in addition to diet therapy, but what are the causes or the consequences I do not possess much information about it. When we go to the UNRWA clinic in the camp, we find huge numbers of diabetic patients and other patients and we have to wait at least 4-6 hours to see the general doctor for very short time. It is impossible to discuss with him your disease because he has not enough time to do so. Our TV and media talk always about the political situation and there is no any space to discuss the heath issues.”

### 8.3.14 To what extent do you have the opportunity for leisure activities?

The diabetic refugees and non-refugees were asked to rate their opportunity for leisure activities on a scale from not at all to completely. The picture that emerged from data on leisure activities is shown in figure (17). About 69% of the refugees had not at all the opportunity for leisure activities, 24% had only a little and about 6% had moderately the opportunity for leisure activities. Only 1% of the refugees had mostly or completely the opportunity for the recreational activities in comparison to about 37% of the non-refugees.

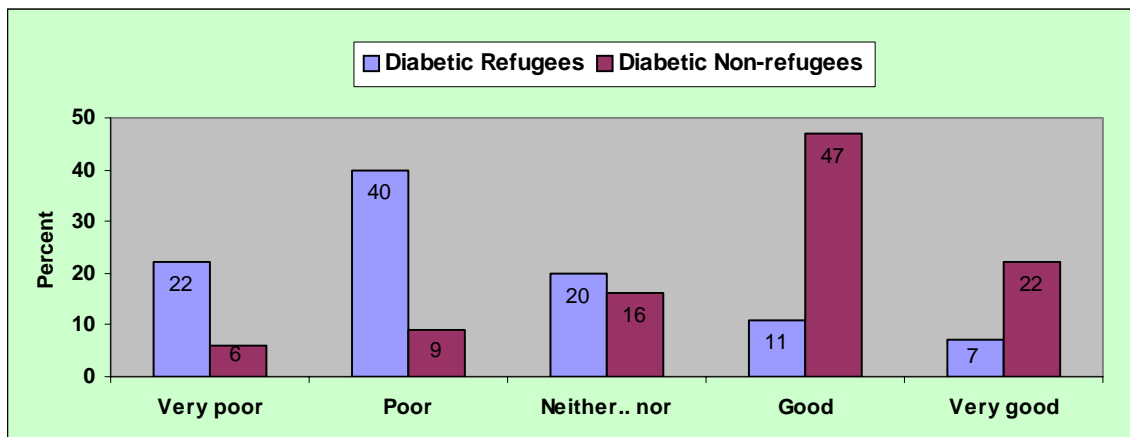


**Figure (17): To what extent do you have the opportunity for leisure activities?**

He said joking: “When we find bread to eat, then we can think about it”. “We don not have here in the camps facilities for leisure time and if we want to go to Gaza to spent a good time there, we need money!! The only thing we find it accessible and cheap is to go to the seashore in the summer. I tried to spend my time in the big mosque in the camps reading Koran or listening to a statement from Sheik.” he continued.

### 8.3.15 How well are you able to get around?

Both groups answered this question on a scale from very poor to very good. In figure (18), about 62% of the cases reported that their ability to get around was either poor or very poor, in comparison to 15% of the controls. Only 18% of the refugees were satisfied with their ability to get around compared with 69% of the diabetic non-refugees.

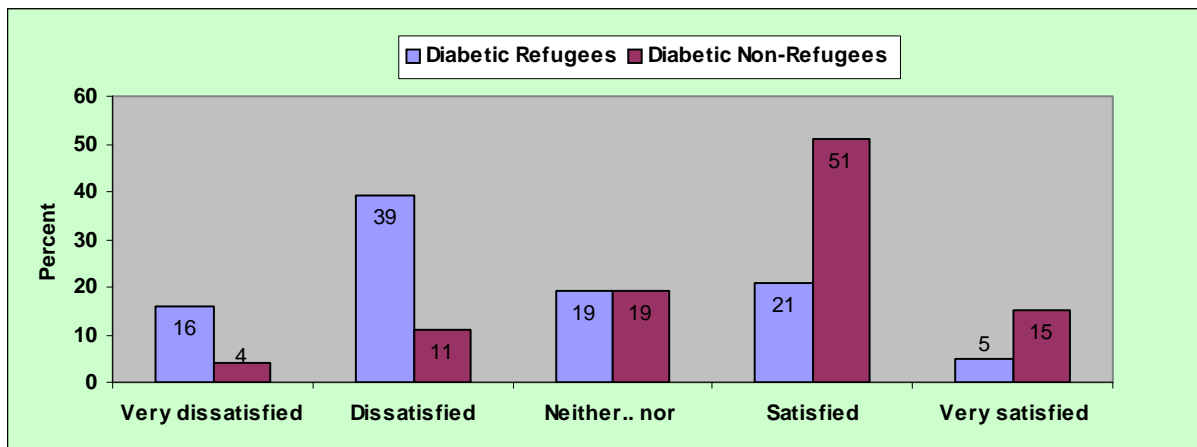


**Figure (18): How well are you able to get around?**

A 68 woman suffered from retinopathy and diabetic foot said: “I can not go outside home because I feel tired very quickly but I can go around at home with help. I have infection in my leg and my “vision” is weak. All of these problems because of the stress I have seen in my life and lastly because of the diabetes”

### 8.3.16 How satisfied are you with your sleep?

The case and control groups were asked to rate their responses to this question on a scale from very dissatisfied to very satisfied. As shown in figure (19), about 55% of the diabetic refugees suffered from sleep disturbances and there were unsatisfied with their sleep pattern, while 15% of the non-refugees reported so. Only 26% of the refugees were satisfied with their sleep in comparison with 66% of the non-refugees.

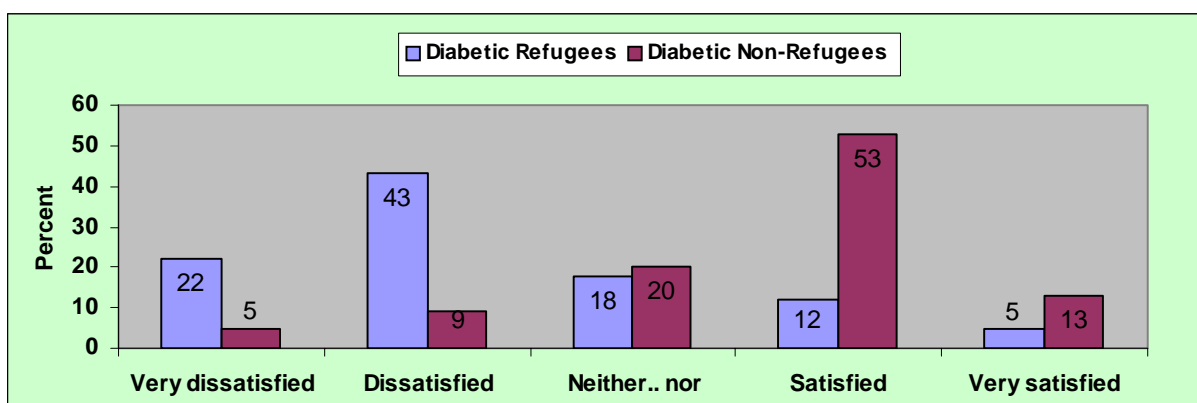


**Figure (19): How satisfied are you with your sleep?**

“So and so” a diabetic refugee man replied. “When I feel pain in my foot I can not sleep but when I take pain medications (he means analgesics) I can sleep well. However, sometimes I have low blood sugar and I sweat so I can not sleep and sometimes I had to go urinate 2 or three times in the night. All of these things interfere with my sleep pattern”. He continued: “Do not forget that we live in a camp near the Israeli settlement of Netzarim, almost every night, we hear fire exchange, military incursions and missile attacks, which interferes with sleeping.

### 8.3.17 How satisfied are you with your ability to perform your daily living activities?

The case and control groups were asked to rate their ability to perform daily living activities on a scale from very dissatisfied to very satisfied. As we see in figure (20), about 22% of the case group was very dissatisfied and about 43% were dissatisfied with their abilities to perform the activity of daily living. Meanwhile, the majority of the control group (66%) was satisfied and very satisfied with their ability to perform daily living activities.



**Figure (20): How satisfied are you with your ability to perform your daily living activities?**

### 8.3.18 How satisfied are you with your capacity for work?

Both groups answered this question on a scale from very dissatisfied to very satisfied. Figure (21) shows that more than 69% of the case group was either dissatisfied or very dissatisfied with their capacity to work. This percentage is consistent with the percentage of the unemployed refugees (table 17) and the average monthly income of them (table 18). On the other side, 53% of the diabetic non-refugees were satisfied with their capacity to work compared with only 12% of the refugees.

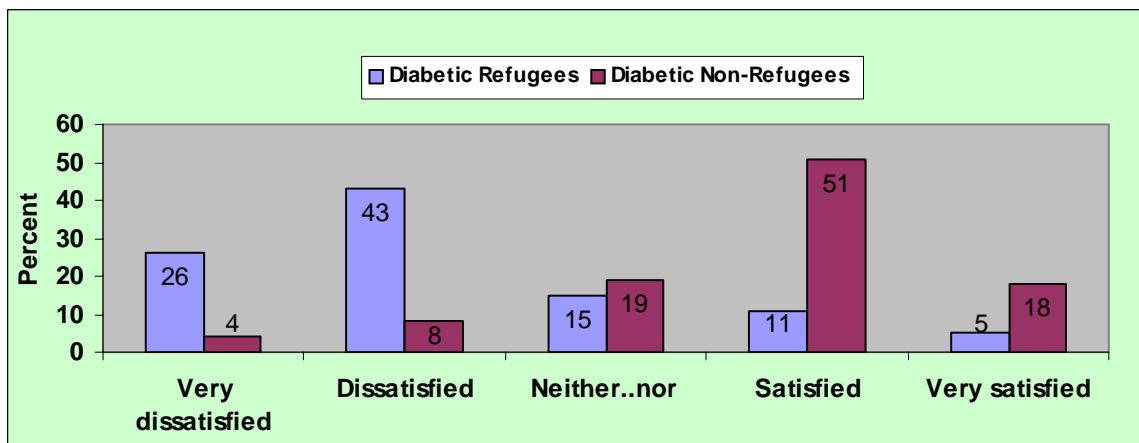
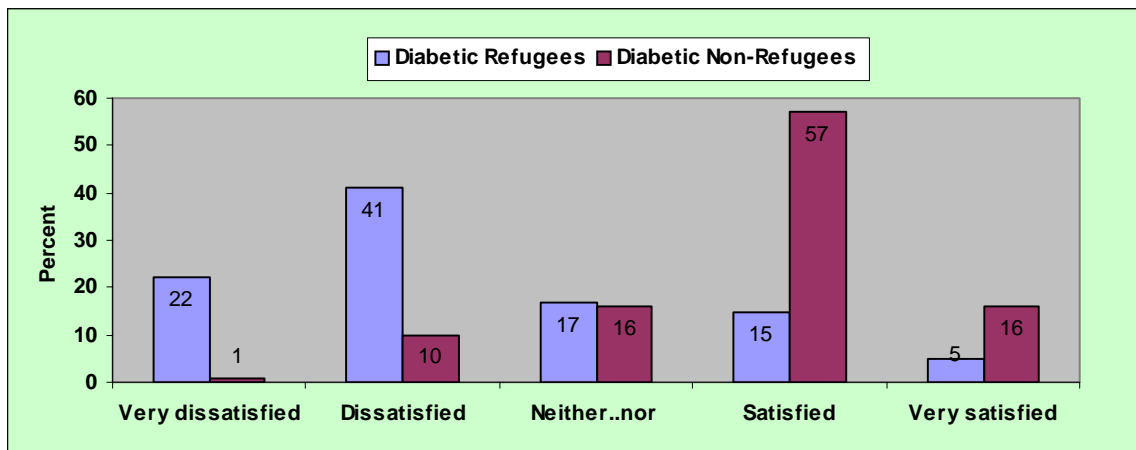


Figure (21): How satisfied are you with your capacity for work?

### 8.3.19 How satisfied are you with yourself?

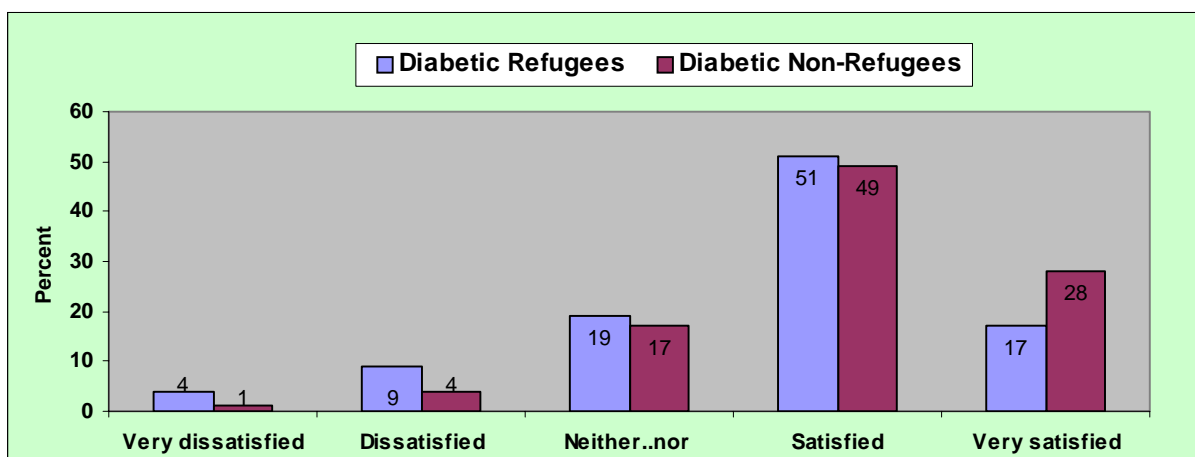
The diabetic refugees and non-refugees were asked to rate the responses for this question on a scale from very dissatisfied to very satisfied. As most of the diabetic refugees in the refugee camps were not satisfied with their capacity for work, had sleep disturbance, suffered from physical pain and complications, and had no leisure activities, the normal consequence for all of these negative aspects was loss of self-satisfaction. This is very evident in Figure (22), as 22% of the diabetic refugees were very dissatisfied and 41% were dissatisfied with themselves, in comparison with only 11% of the diabetic non-refugees. On the other hand, about 36% of the cases were relatively satisfied with themselves although some of them experienced many difficulties with the disease.



**Figure (22): How satisfied are you with yourself?**

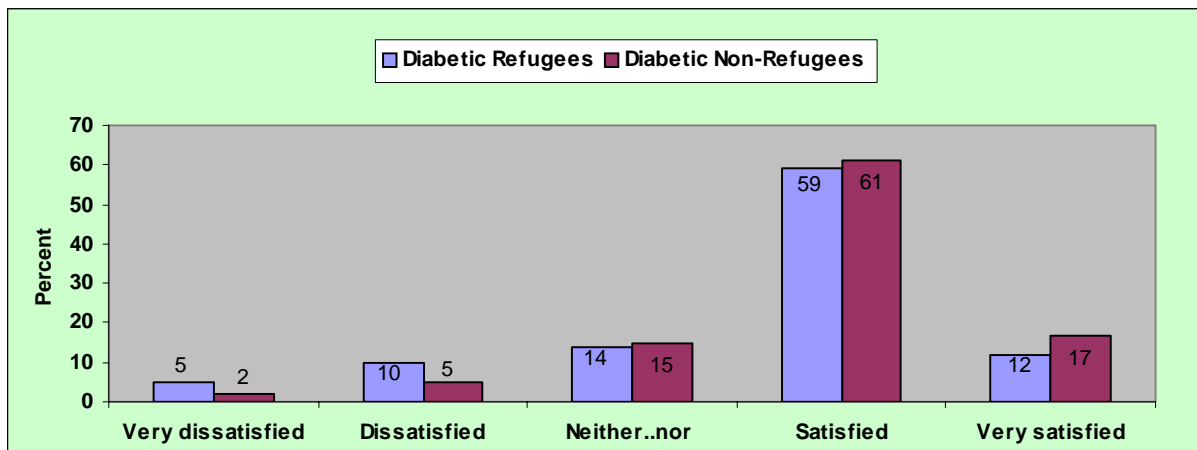
### 8.3.20 Social life: Satisfaction with personal relationships and the support from friends

The diabetic refugees and non-refugees were asked to rate their satisfaction with their personal relationship and the support they get from their friends on a scale from very dissatisfied to very satisfied. These two questions have been integrated and presented here in one unit, because they are complementary to each other and very difficult to be separated. According to figures (23) & (24) the majority of the case group (68%) and the control group (77%) were satisfied and very satisfied with their personal relationships. Also, about 71% of the cases and 78% of the controls were very satisfied and satisfied with the support they got from their friends. Despite the importance of the social activities for the refugees, there is still a minority of the cases (13%) and controls (7%) who were not satisfied with their personal relationships and the support they got from their friends.



**Figure (23): How satisfied are you with your personal relationships?**



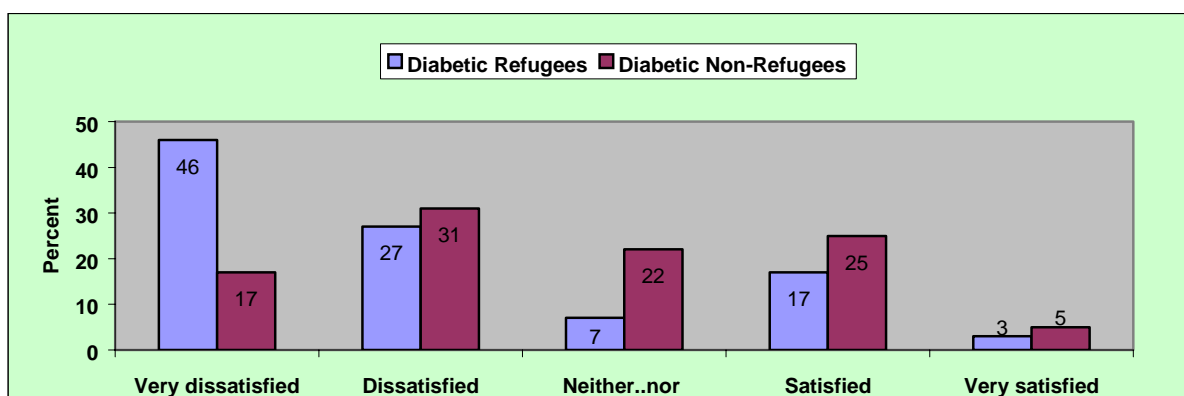


**Figure (24): How satisfied are you with the support you get from your friends?**

A 60 years old diabetic refugee said: “My social relationship is very good. I visit my friends and my relatives always and the visited me. When I am sick they come to me directly. When we have any occasion, we invited the neighbors and the relatives and they come. Sometimes they come to us without invitation. Really I am satisfied with all of my personal relationship”.

### 8.3.21 How satisfied are you with your sex life?

The case and control groups were asked to rate their responses to this question on a scale from very dissatisfied to very satisfied. As shown in figure (25), about 73% of the diabetic refugees (cases) were dissatisfied and very dissatisfied with their sexual life and more than 48% of the diabetic non-refugees (control) were so. Only 20% of the diabetic refugees and 30% of the non-refugees were satisfied with their sexual life.



**Figure (25): How satisfied are you with your sex life?**

Citation from the interview with the 55 years old diabetic refugee: At the beginning he was reluctant to speak about this point, but with some probing and indirect questions he said: ”At the beginning of my disease (before 13 years) there were no any problems with my sexual life, but since three years I started to feel some problems such as (erectile

disturbances). I feel that my sexual desire is decreasing, I don't know why!! Really, this is a very shameful for me and sometimes I feel very depressive because I can not do this thing as before. I went to a doctor several times but I feel no improvement. And this causes for me a big stress”.

A 45 years old diabetic refugee woman diagnosed with diabetes for 11 years and her blood sugar is always uncontrolled, said: “I feel embarrassed to talk about this. But, really, I have a problem in the sexual life with my husband. It is very often that I feel no desire to do some thing. Also, when something happens with my husband I feel it painful. Very often I did it only to satisfy him and I pretend that every thing is OK. Really, this is as a nightmare for me. This problem started for 4 years, may be because my diabetes is very difficult to control”.

### 8.3.22 How satisfied are you with the conditions of your living place?

Both groups answered this question on a scale from very dissatisfied to very satisfied. As shown in figure (26), more than 78% of the diabetic refugees were extremely dissatisfied with their living conditions, about 10% were neither satisfied nor dissatisfied, about 8% were satisfied, and only 4% were very satisfied. For the diabetic non-refugees who live in the cities, about 48% were satisfied with their living conditions and about 20% were very satisfied.

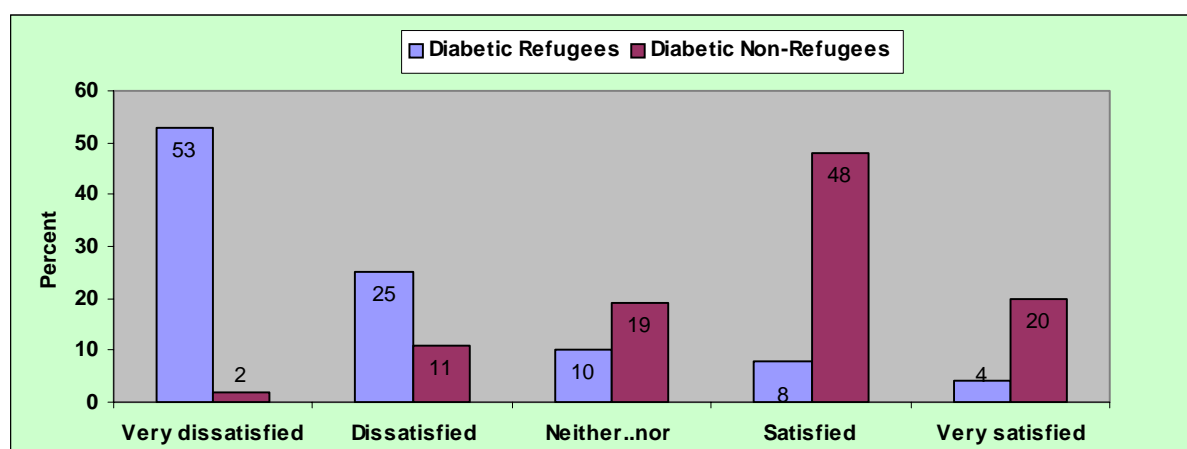
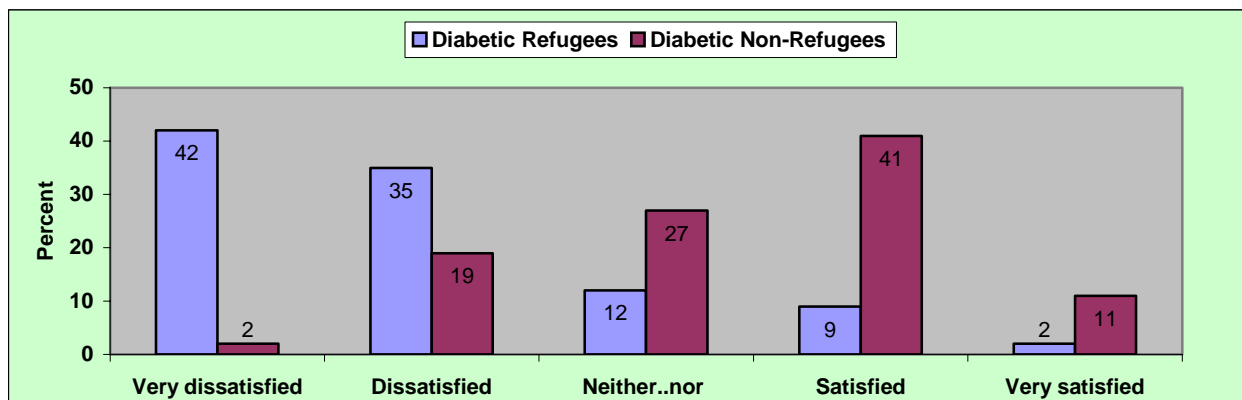


Figure (26): How satisfied are you with the conditions of your living place?

### 8.3.23 How satisfied are you with your transport?

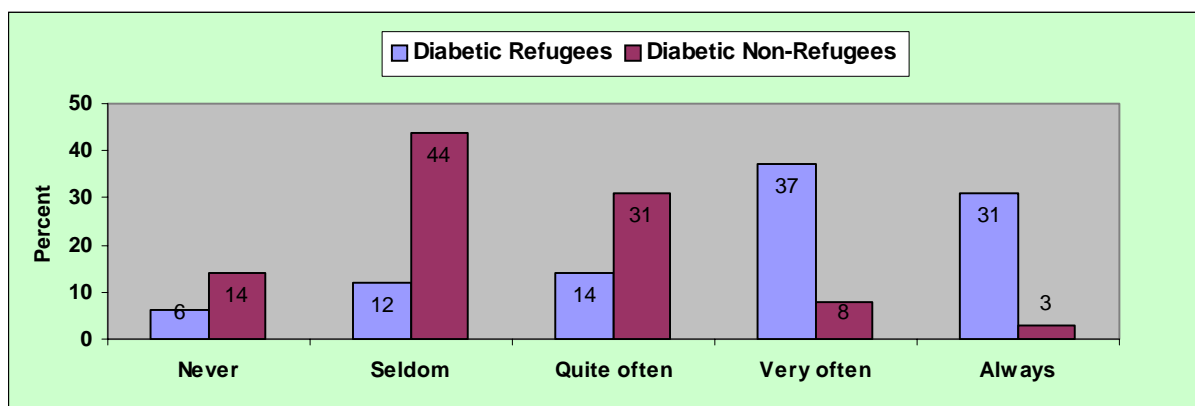
The case and control groups were asked to rate their responses to this question on a scale from very dissatisfied to very satisfied. According to figure (27), most of the diabetic refugees (77%) were dissatisfied and very dissatisfied with their transport. Regarding the non-refugees, about 41% of them were satisfied and 11% were very satisfied with their transportation; this is mainly related to the better economic situation and their ability to buy private cars.



**Figure (27): How satisfied are you with your transport?**

### 8.3.24 How often do you have negative feelings such as blue mood, despair, anxiety, depression?

The two groups were asked to rate the responses to this item on a scale from never to always. The results in figure (28) shows that about 82% of the diabetic refugees had negative feelings such as blue mood, despair, anxiety, depression quite often, very often, and always. While only 18% of the refugees said that they had never or seldom experienced such negative feelings. In contrary, about 58% of the control group reported that they never or seldom had such feelings.



**Figure (28): How often do you have negative feelings such as blue mood, despair, anxiety, depression?**

A diabetic refugee man continued sadly: “I experience most of these feelings very often. When I deeply think about my self and my disease and my difficult financial status, I lose my desire in the life. Sometimes I lose the hope to get out from such crises. Very often I become very quickly nervous and I do not talk with any one. All of these bad feelings make me unable to think positively about my disease and my family”.

## 8.4 Analysis of variance of quality of life domains among the diabetic refugees (the case group) and the diabetic non-refugees (1<sup>st</sup> control group).

ANOVA test is used to determine the effects of the more than two levels of independent variables on the dependent variable. The F-test will create such a ratio comparing the variation of the level of the independent variable and the variations within the samples.

### 8.4.1 The effect of refuge life on the QOL domains of the diabetic refugees by comparison of means

This section is a complementary part to the crosstabulations of the differences between the diabetic refugees and non-refugees regarding the items of the WHOQOL-BREF (refer to 8.3.1 through 8.3.24). In this section the means of the quality of life domains of the diabetic patients were verified according to the living place (refugees vs. non-refugees), in order to identify the effect of the refuge life on the QOL of the diabetic refugees in Gaza strip.

According to the table (24), the mean quality of life in physical domain of the diabetic refugees was 36.69, psychological domain 34.79, social domain 52.40, and environmental domain 23.43. In contrary, the means of the QOL domains among the diabetic non-refugees were as follows: 67.84 in physical domain, 67.22 in psychological domain, 62.90 in social domain, and 61.01 in environmental domain. The global value of the QOL for the case was 33.53 while the global value for the control group was 64.01. Overall, mean quality of life domains among the case group is less than the control group. The best QOL domain for the diabetic refugees was the social, while the worst QOL domain was the environmental.

**Table (24): The effect of refuge life on the QOL domains of the diabetic refugees by comparison of means**

Group		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Diabetic Refugees	Mean	36,69	34,79	52,40	23,43	33,53
	N	197	197	197	197	197
	SD	25,17	24,51	21,06	18,99	20,92
Diabetic Non-refugees	Mean	67,84	67,22	62,90	61,01	64,01
	N	197	197	197	197	197
	SD	21,44	18,43	19,22	17,58	16,86

**8.4.2 The differences of the QOL domains between the diabetic refugees and non-refugees by using one-way ANOVA test.**

The ANOVA output table (25) shows strong and significant differences between the diabetic refugees and non-refugees regarding the four QOL domains. As shown in the table, the most significant difference was found in the environmental domain (F 415.25, Sig. 0.001), then the psychological domain (F 220.22, Sig. 0.001), then the physical domain (F 174,81, Sig. 0.001), whilst the least significant domain was the social domain. Moreover, the overall difference in the global value between the two groups was highly significant as indicated by the F ratio: 253.40 with a significant level: 0.001.

**Table (25): The differences of the QOL domains between the diabetic refugees and non-refugees by using one-way ANOVA test**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	95559,63	1	95559,63	174,81	,001
	Within Groups	214285,84	392	546,64		
	Total	309845,48	393			
Psychological domain	Between Groups	103569,90	1	103569,90	220,22	,001
	Within Groups	184356,05	392	470,29		
	Total	287925,95	393			
Social domain	Between Groups	10864,87	1	10864,87	26,72	,001
	Within Groups	159358,48	392	406,52		
	Total	170223,36	393			
Environmental domain	Between Groups	139097,48	1	139097,48	415,25	,001
	Within Groups	131308,30	392	334,97		
	Total	270405,78	393			
Global value	Between Groups	91522,90	1	91522,90	253,40	,001
	Within Groups	141579,99	392	361,17		
	Total	233102,89	393			

( $P < 0.05$ )

### **8.4.3 Age and quality of life domains of the diabetic refugees and non-refugees by comparison of means**

The age distribution among the case group and the first control group showed that 25% of the subjects were between the ages of 40-49 years, and 58% were above 50 years old. The comparison of means and one-way ANOVA test (F-ratio) followed by Post Hoc multiple comparisons were used to compare the effect of age on the QOL domains for the diabetic refugees and non-refugees. For the diabetic refugees (the case group), table (26) shows that the mean QOL of physical domain ranged from 50.75 for the age group (less than 30 years) to 21.69 for the age group (more than 60 years). The mean QOL of the psychological domain decreased from 44.83 for the group (less than 30), to 24.08 for the age group (more than 60 years). The social domain, however, had the better QOL mean scores (58.41) and there was no huge difference between the highest and the lowest mean scores within the different age groups. Meanwhile, the mean of the environmental domain represented the lowest mean score among the four QOL domains of the diabetic refugees. It started with 30.25 for the age group (less than 30), then decreased to 28.61 for the age group (40-49), and finally reached the lowest value (16.44) for the age group (more than 60 years). For the control group (diabetic non-refugees), we can see in table (28), that the age has no systematic effect on the QOL domain within the different age groups. In physical domain, for example, the age groups (less than 30), (30-39), and (50-60) had the means of 68.41, 77.00, and 72.34 respectively. In contrast with the case group, the physical and psychological domains have the best means (77.00 and 75.61) among the QOL domains.

**Table (26): Age and QOL domains of the diabetic refugees and non-refugees by comparison of means**

Group	Age		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Diabetic Refugees	Less than 30	Mean	50,75	44,83	58,41	30,25	43,33
		SD	31,50	35,26	27,32	24,59	28,63
	30-39 years	Mean	47,14	41,66	57,71	29,00	41,00
		Sd	28,94	27,70	23,66	22,49	23,36
	40-49 years	Mean	48,46	45,32	57,77	28,61	41,81
		SD	27,93	28,73	22,57	19,44	23,62
	50-60 years	Mean	33,21	30,92	52,01	21,75	31,04
		SD	18,98	19,11	19,40	17,79	17,33
	More than 60	Mean	21,69	24,08	43,79	16,44	23,00
		SD	16,04	15,20	16,13	14,48	12,96
	Total	Mean	36,69	34,79	52,40	23,43	33,53
		N	197	197	197	197	197
SD		25,17	24,51	21,06	18,99	20,92	
Diabetic Non-refugees	Less than 30	Mean	68,41	59,50	62,16	54,33	60,08
		SD	8,07	16,63	28,03	15,52	13,740
	30-39 years	Mean	77,00	75,61	69,47	66,85	71,47
		SD	12,88	15,124	20,85	13,95	12,26
	40-49 years	Mean	72,34	67,57	64,93	60,08	65,20
		SD	18,26	16,75	16,26	16,22	14,65
	50-60 years	Mean	69,46	70,90	65,42	63,12	66,62
		SD	19,21	15,79	17,64	16,97	15,64
	More than 60	Mean	57,08	60,20	54,83	58,22	57,08
		SD	27,92	22,24	19,04	20,78	20,51
	Total	Mean	67,84	67,22	62,90	61,01	64,01
		N	197	197	197	197	197
SD		21,44	18,43	19,22	17,58	16,86	

**8.4.4 Age and quality of life domains of the diabetic refugees and non-refugees by F-ratio.**

As shown in table (27), there are significant effects among the age of the case and control and three of the QOL domains. These domains are: physical domain (F 9.732, Sig. 0.001), psychological domain (F 4.630, Sig. 0.001), and social domain (F 6.041, Sig. 0.001). Meanwhile, no significant effect was found between age and the environmental domain (F 1.518, Sig. 0.196). This indicated that the environmental factors that the refugees experienced (compacted houses,

lack of clean water, air pollution, etc.) affected all the population regardless of their age group.

**Table (27): Age and QOL domains of the diabetic refugees and non-refugees by F-ratio**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	28186,26	4	7046,56	9,73	,001
	Within Groups	281659,21	389	724,06		
	Total	309845,48	393			
Psychological domain	Between Groups	13084,65	4	3271,16	4,63	,001
	Within Groups	274841,30	389	706,53		
	Total	287925,95	393			
Social domain	Between Groups	9955,96	4	2488,99	6,04	,001
	Within Groups	160267,40	389	411,99		
	Total	170223,36	393			
Environmental domain	Between Groups	4155,43	4	1038,86	1,51	,196
	Within Groups	266250,35	389	684,44		
	Total	270405,78	393			
Global value	Between Groups	12219,65	4	3054,91	5,38	,001
	Within Groups	220883,23	389	567,82		
	Total	233102,89	393			

( $P < 0.05$ )

#### 8.4.5 Post Hoc comparisons among the age and quality of life domains of the diabetic refugees and non-refugees by using Scheffe technique

“Scheffe post-hoc” table (Appendix D) provides comparisons of means for each age group against each other age group regarding every QOL domain. In physical domain significant differences were found between the age group of (more than 60 years) and the other age groups (less than 30 years, mean differences 20.19), (30-39 years, mean difference 22.68), (40-49 years, mean difference 21.02) and (50-60 years, mean differences 11.95). In the psychological domain also, there were significant differences between the age group of (more than 60 years) and the age groups (30-39 years) and (40-49 years) with mean differences 16.50 and 14.30 respectively. For social domain, statistically significant effects were located among the age group (>60 years) and (30-39 years), (40-49 years) and (50-60 years) age groups, with mean differences 14.27, 12.04, 9.40 respectively. However, no significant differences were captured in the post hoc table for the environmental domain as indicated previously by the ANOVA test. This confirmed that the bad environment negatively affected all the age groups.



#### 8.4.6 Gender and quality of life domains of the diabetic refugees and non-refugees by comparison of mean

As evidenced by the table (28), the males in the case group (diabetic refugees) had mean quality of life in physical domain 44.36, psychological domain 43.93, social domain 58.89, and environmental domain 30.27, compared with 71.62 in physical domain, 66.74 in psychological domain, 62.04 in social domain, and 60.92 in environmental domain among the males in the control group. The mean quality of life in physical domain is 28.11, psychological domain 24.5806, social domain 45.13, and environmental domain is 15.77 among the females of diabetic refugees. While the females of the diabetic non-refugees had the mean score of 63.61 in physical domain, 67.76 in psychological domain, 63.8602 in social domain, and 61.10 in environmental domain. On the other hand, the women in the control group scored better global value of QOL (62.97) in comparison with women in the case group (24.88) because they had better chances to get jobs, to access to the medical care and to get education. Interestingly, the best QOL domain for the males and the females was the social domain (60.47 and 54.50 respectively).

**Table (28): Gender and quality of life domains of the diabetic refugees and non-refugees by comparison of mean**

Group	Gender		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Diabetic Refugees	Male	Mean	44,36	43,93	58,89	30,27	41,26
		N	104	104	104	104	104
		SD	25,70	23,98	18,48	19,11	20,72
	Female	Mean	28,11	24,58	45,13	15,77	24,88
		N	93	93	93	93	93
		SD	21,66	20,89	21,48	15,71	17,58
Diabetic Non-refugees	Male	Mean	71,62	66,74	62,04	60,92	64,94
		N	104	104	104	104	104
		SD	20,96	20,127	22,12	19,52	18,21
	Female	Mean	63,61	67,76	63,86	61,10	62,97
		N	93	93	93	93	93
		SD	21,28	16,41	15,41	15,22	15,24

#### 8.4.7 Comparison of QOL domains and gender of the diabetic refugees and non-refugees by using (F) test

According to table (29), the variances of mean squares, F values, and levels of significance between and within groups indicate a significant effect between QOL domains and gender as evidence by physical domain (F 19.17, Sig. 0.001), psychological domain (F 11.55, Sig. 0.001), social domain (F 8.23, Sig. 0.004), environmental domain (F 7.43, Sig. 0.007) and global value (F 14.41, Sig. 0.001). It is obvious that sex (independent variable) had a real effect on the QOL (dependent variable) and SSB is really an estimation of the same population variance (sigma) plus the effects of the independent variable.

**Table (29): Comparison of QOL domains and gender of the diabetic refugees and non-refugees by using (F) test**

QOL domain		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	14446,84	1	14446,84	19,171	,001
	Within Groups	295398,63	392	753,56		
	Total	309845,48	393			
Psychological domain	Between Groups	8247,02	1	8247,02	11,559	,001
	Within Groups	279678,93	392	713,46		
	Total	287925,95	393			
Social domain	Between Groups	3501,03	1	3501,03	8,232	,004
	Within Groups	166722,32	392	425,31		
	Total	170223,36	393			
Environmental domain	Between Groups	5034,06	1	5034,06	7,436	,007
	Within Groups	265371,72	392	676,96		
	Total	270405,78	393			
Global value	Between Groups	8267,13	1	8267,13	14,414	,001
	Within Groups	224835,76	392	573,56		
	Total	233102,89	393			

( $P < 0.05$ )

#### 8.4.8 The effect of Type 1 and Type 2 diabetes on the means of the QOL domains among the diabetic refugees and non-refugees by comparison of means

To identify the effect of Type I and Type 2 diabetes on the QOL for the diabetic refugees and non-refugees, the comparison of means and one-way ANOVA test (F-ratio) were used. For the Type 1 diabetic patients, table (30) shows that the mean QOL of physical domain was 60.80, psychological domain 54.63, social domain 62.63, and for the environmental domain the mean was 45.50. Meanwhile, the mean of QOL for the Type 2 diabetic patients was 51.56 in the physical domain, 50.71 in the psychological domain, 57.24 in the social domain and 41.95 in the environmental domain. As we can observe from the above results that the means of the QOL domains for Type 1 diabetics were slightly better than those for Type 2. However, these differences among the means were not so big to reach a significant effect – as it will be discussed in the next section by F-ratio.

**Table (30): The effect of Type 1 and Type 2 diabetes on the means of the QOL domains among the diabetic refugees and non-refugees by comparison of means**

Type of Diabetes		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Type 1	Mean	60,80	54,63	62,63	45,50	53,86
	N	30	30	30	30	30
	SD	23,68	28,22	25,33	24,57	23,46
Type 2	Mean	51,56	50,71	57,24	41,95	48,35
	N	364	364	364	364	364
	SD	28,32	26,98	20,38	26,37	24,40
Total	Mean	52,26	51,01	57,65	42,22	48,77
	N	394	394	394	394	394
	SD	28,07	27,06	20,81	26,23	24,35

#### 8.4.9 The differences between the means of QOL domains among Type 1 and Type 2 diabetic patients in the case group and 1<sup>st</sup> control group by using one way ANOVA test

According to the findings shown in table (31), all of the calculated F-values were either less than one as in the psychological and environmental domains (0.581 and 0.507 respectively) or a little bit more as in the physical, social and global domains (3.013, 1.864, and 1.421 respectively).

Moreover, all of the Significance Levels of the all domains were more than 0.05 (0.083, 0.446, 0.173, 0.477) as shown in the last column. Clearly, we can conclude that no significant effects were found between the means of QOL domains of Type 1 and Type 2 diabetics; and the slight improvement in the QOL for the Type 1 participants was either real but not significant or due to random error.

**Table (31): The differences between the means of QOL domains among Type 1 and Type 2 diabetic patients in the case and 1<sup>st</sup> control groups by using one way ANOVA test**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	2363,26	1	2363,26	3,013	,083
	Within Groups	307482,21	392	784,39		
	Total	309845,48	393			
Psychological domain	Between Groups	426,28	1	426,28	,581	,446
	Within Groups	287499,67	392	733,41		
	Total	287925,95	393			
Social domain	Between Groups	805,67	1	805,67	1,864	,173
	Within Groups	169417,69	392	432,18		
	Total	170223,36	393			
Environmental domain	Between Groups	349,17	1	349,17	,507	,477
	Within Groups	270056,61	392	688,92		
	Total	270405,78	393			
Global value	Between Groups	842,14	1	842,14	1,421	,234
	Within Groups	232260,75	392	592,50		
	Total	233102,89	393			

( $P < 0.05$ )

#### **8.4.10 The impact of the duration of diabetes on the QOL domains among the diabetic refugees and non-refugees by comparing the means.**

To investigate how longer duration of diabetes affects the QOL among the case and control groups, the means of QOL domains were compared in table (32). It is observed that in the first year of diagnosis the QOL scores were (Mean  $41.4 \pm 22.3$ ) in the physical domain, (Mean  $39.5 \pm 24.4$ ) in the psychological domain, (Mean  $55.0 \pm 25.1$ ) in the social domain and (Mean  $25.8 \pm 18.6$ ) in the environmental domain; while within 2-5 years duration of diabetes, the total QOL values have improved to reach (Mean  $51.8 \pm 28.3$ ) in the physical domain, (Mean  $48.1 \pm 28.5$ ) in the psychological domain, (Mean  $60.3 \pm 20.1$ ) in the social domain and (Mean  $31.6 \pm 22.2$ ) in the

environmental domain. But after five years of diagnosis, the total QOL values started to decline again to reach the worst values after 10 years of diagnosis (Means: 27.2; 26.1; 46.3 and 18.2 for the physical, psychological, social and environmental domain respectively). It is also worthy to observe that the psychological domain of newly diagnosed refugees was low compared with the physical and social domains, but after 10 years of having diabetes, the physical and psychological domains were almost the same but low.

**Table (32): The impact of the duration of diabetes on the QOL domains among the diabetic refugees by comparing the means**

The first time to know that you have diabetes		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
One year ago	Mean	41,40	39,53	55,00	25,86	38,06
	N	15	15	15	15	15
	SD	22,38	24,45	25,08	18,64	19,75
2-5 years ago	Mean	51,85	48,08	60,35	31,66	45,10
	N	56	56	56	56	56
	SD	28,31	28,54	20,05	22,22	23,67
6-10 years ago	Mean	31,76	30,75	50,93	20,83	30,00
	N	60	60	60	60	60
	SD	21,75	21,09	18,27	16,43	18,30
More than 10 years ago	Mean	27,24	26,12	46,39	18,25	25,89
	N	66	66	66	66	66
	SD	19,45	18,46	21,53	16,00	16,35
Total	Mean	36,69	34,79	52,40	23,43	33,53
	N	197	197	197	197	197
	SD	25,17	24,51	21,06	18,99	20,92

#### **8.4.11 The impact of the duration of diabetes on the QOL domains among the diabetic refugees and non-refugees by using F-ratio.**

In addition to the comparisons of means, ANOVA and F-test were used to detect the effect of the different duration periods of diabetes on the overall QOL of the diabetic refugees and non-refugees. According to the table (33), F-ratio for the physical domain was 20.13 with a significance level of 0.001, F-ratio for the psychological domain was 17.76 with a significance level of 0.001, F-ratio for the social domain was 13.42 with a significance level of 0.001, F-ratio for the environmental domain was 14.26 with a significance level of 0.001, and F-ratio for the

global value was 19.78 with a significance level of 0.001. It is very clear from these results that there were significant associations between the duration of diabetes and QOL. The strongest association was found between the physical domain and QOL (F 20.13, Sig. 0.001) especially after five years of the diagnosis. On the other side, the psychological domain was found to have the second significant association with the duration of diabetes (F 17.76, Sig. 0.001). However, as we have pointed in the last section, that the psychological domain had the most significant association in the first year, then it started to decrease within 2-5 years after the diagnosis.

**Table (33): The impact of the duration of diabetes on the QOL domains among the diabetic refugees and non-refugees by using F-ratio**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	41544,37	3	13848,126	20,13	,001
	Within Groups	268301,10	390	687,95		
	Total	309845,48	393			
Psychological domain	Between Groups	34608,81	3	11536,27	17,76	,001
	Within Groups	253317,14	390	649,53		
	Total	287925,95	393			
Social domain	Between Groups	15937,89	3	5312,63	13,42	,001
	Within Groups	154285,46	390	395,60		
	Total	170223,36	393			
Environmental domain	Between Groups	26742,89	3	8914,30	14,26	,001
	Within Groups	243662,89	390	624,77		
	Total	270405,78	393			
Global value	Between Groups	30790,57	3	10263,52	19,78	,001
	Within Groups	202312,32	390	518,75		
	Total	233102,89	393			

( $P < 0.05$ )

#### **8.4.12 Multiple comparisons of the significant differences between the duration of diabetes and the QOL domains among the diabetic refugees and non-refugees by using Scheffe test.**

Based on the ANOVA table (33) in the last section, significant differences were found among the different duration periods of diabetes and the four QOL domains and global value. But, what was the nature of these differences and where did they locate?. According to post-hoc table in appendix (E), the patients who had diabetes for 6-10 years had significant differences with all other duration periods (2-5 years and more than 10 years) except (one year ago) in the physical

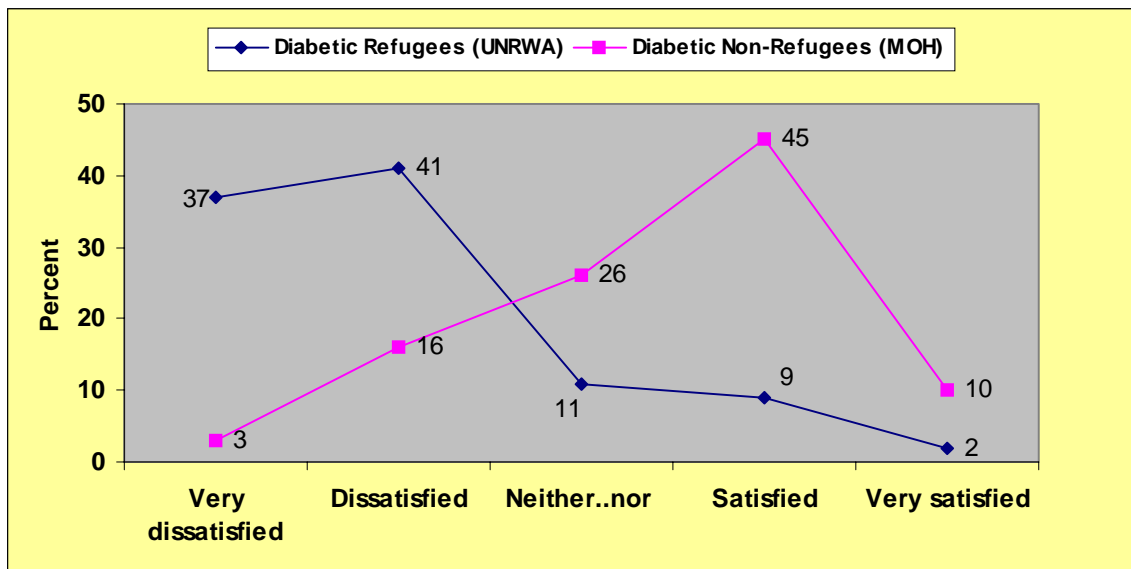
and psychological and global domains, while the patients who were diagnosed for more than 10 years had significant differences with all other duration periods (one year, 2-5 years and 6-10 years) in all QOL domains.

### **8.5 Comparison between the health services provided by the Palestinian Ministry of Health (PMOH) and by UNRWA for the diabetic patients in Gaza Strip.**

It is well known that PHC centers are the main venues for regular and systematic care for diabetic patients. Management services for NCDs care are integrated within the PHC centers at MOH & UNRWA centers. UNRWA health centers provide health services free for all eligible registered refugees including NCDs management at primary health care level. MOH centers provide health services for NCDs patients who have valid health insurance. Hospitalization services provided through the MOH hospitals are free for clients covered by health insurance while NGOs' hospital services provided at high cost. UNRWA reimburses the refugees who are referred and admitted to MOH hospitals according to agency regulations.

The diabetic refugees and non-refugees were asked to rate their satisfaction with the health services provided for them by the MOH and UNRWA on a scale from very dissatisfied to very satisfied. Then they were asked to explain why they were satisfied or dissatisfied.

Regarding the health services of UNRWA, about 37% of the diabetic refugees were very dissatisfied, 41% were dissatisfied, 11% neither satisfied nor dissatisfied, 9% were satisfied, and 2% were very satisfied (figure 29). This indicates that the majority of the diabetic refugees (78%) were not satisfied with the health care provided by the UNRWA centers in the refugee camps in Gaza strip. According to the qualitative approach, the major source of their dissatisfaction was the crowdedness of the clinics and the disproportionate number of health personnel to the number of clients. Regarding the health services of the PMOH, about 3% of the diabetics were very dissatisfied, 16 % were dissatisfied, 26% neither satisfied nor dissatisfied, 45% were satisfied, and 10% were very satisfied (figure 29). Obviously, more than the half (55%) of the clients who had health insurance and were eligible to receive the health care provided by the Ministry of Health (MOH) expressed their satisfaction with that care especially in Gaza city, mostly because of the adequate and regular care they received either in the clinics or at the hospitals.



**Figure (29): Satisfaction with health services**

A 55 years old diabetic refugee said: “I am not satisfied with the health services provided for us by UNRWA. There is only one general doctor in the morning shift and another one for the afternoon shift for more than 100-150 patients daily. I have to wait 4-6 hours to see the doctor only for minutes. He does not perform complete examination; he just asks me about my problem and sometimes before I complete my speaking he writes the prescription. A general doctor is not enough; we need to be examined by diabetologist at least once every month. The staffs there behave with us impolitely. They do not educate us about our disease and how to deal with it in a critical situation. For example, I take the insulin and pills since long time but what are the differences between the both? I don’t know. What are the side effects for insulin and what to do in case of its occurrence?!! Also I don’t know”.

**8.6 The impacts of diabetes-related complications on the QOL domains among the diabetic refugees and the diabetic non-refugees in Gaza strip.**

People with diabetes are at increased risk of cardiovascular, peripheral vascular and cerebrovascular disease. Although it is now evident to reduce the incidence of complications, or when they occur, retard their progression, their prevalence and incidence remain unacceptably high (Ekoe & Zimmet, 2001). This section will discuss the effect of these complications on the QOL domains among the refugees and the non-refugees in Gaza strip.



### 8.6.1 The effect of complications on the QOL of the diabetic refugees (case group) by ANOVA test and comparison of means

According to the ANOVA table (34), very clear significant effects were captured among the different types of diabetes-related complications and the means of QOL domains. Obviously, the most significant effect of the complications was on the physical domain (F 95.13 & Sig. 0.001), then on the psychological domain (F 64.20 & Sig. 0.001), while the least significant effect of the complications was on the social domain (F 15.14 & Sig. 0.001). This indicated that diabetic complications (blindness, dialysis, symptomatic neuropathy, foot ulcers, amputation, stroke, and congestive heart failure) were associated with more substantial reductions not only in the physical abilities of the refugees but also in their psychological wellness. Many of them suffered from depressive symptoms, which have a great impact on the individual's functional ability and quality of life.

**Table (34): The effect of complications on the QOL domains of the diabetic refugees (case group) by ANOVA test**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	88608,85	5	17721,77	95,13	,001
	Within Groups	35578,86	191	186,27		
	Total	124187,72	196			
Psychological domain	Between Groups	73841,98	5	14768,39	64,20	,001
	Within Groups	43935,89	191	230,03		
	Total	117777,87	196			
Social domain	Between Groups	24686,65	5	4937,33	15,14	,001
	Within Groups	62254,66	191	325,94		
	Total	86941,32	196			
Environmental domain	Between Groups	32895,04	5	6579,00	33,24	,001
	Within Groups	37801,27	191	197,91		
	Total	70696,32	196			
Global value	Between Groups	56337,8	5	11267,56	72,92	,001
	Within Groups	29513,20	191	154,51		
	Total	85851,03	196			

( $P < 0.05$ )

In order to deeply analyze the specific differences between the complications of diabetes among the refugees and the four domains of the Quality of life, the comparison of means in table (35)

was developed by using the SPSS. In this table three comparisons have been observed. First, it is found that the patients who did not develop any complication had better means of the QOL domains (Physical domain 77.82, Psychological domain 72.71, Social domain 73.38, and Environmental domain 48.53) than those who had only one complication (e.g., Diabetic foot: Physical domain 31.42, Psychological domain 28.50, Social domain 48.53, and Environmental domain 19.92). Second, patients without complications had better QOL mean scores than those patients who suffered from more than one complication (Physical domain 19.09, Psychological domain 20.14, Social domain 45.50, and Environmental domain 13.75). Third, the diabetic refugees who had one complication achieved higher QOL scores than those who suffered from more than one complication.

**Table (35): Effect of complications on QOL domains of case group by comparison of means**

Group	Complications of Diabetes	Physical domain	Psychological domain	Social domain	Environmental domain	Global value	
Diabetic Refugees	Retinopathy	Mean	31,69	29,84	47,43	19,97	29,12
		N	39	39	39	39	39
		SD	10,897	15,90	19,75	16,22	12,72
	Nephropathy	Mean	36,08	34,91	61,41	25,50	35,91
		N	12	12	12	12	12
		SD	9,326	5,23	10,65	20,09	8,17
	Neuropathy	Mean	28,58	23,88	41,17	14,11	23,29
		N	17	17	17	17	17
		SD	11,10	13,60	20,39	10,77	11,09
	Diabetic foot	Mean	31,42	28,50	48,53	19,92	29,42
		N	26	26	26	26	26
		SD	12,50	12,32	18,56	10,146	9,50
	Nothing	Mean	77,82	72,71	73,38	48,53	66,30
		N	39	39	39	39	39
		SD	19,05	21,87	18,22	19,08	18,23
	More than one complication	Mean	19,09	20,14	45,50	13,75	20,18
		N	64	64	64	64	64
		SD	12,86	12,01	17,03	8,97	9,56
Total	Mean	36,69	34,79	52,40	23,43	33,53	
	N	197	197	197	197	197	
	SD	25,17	24,51	21,06	18,99	20,92	

For the diabetic refugees, the total mean of the social domain remains the best one (52.40) in comparison with the other domains (Physical domain 36.69, Psychological domain 34.79, Environmental domain 23.43, and Global domain 33.53). Patients who suffered from visual impairment (retinopathy) and diabetic foot considered the physical environment around very bad (19.97 and 19.92 respectively).

### 8.6.2 The effect of complications on the QOL of the diabetic non-refugees (1<sup>st</sup> control group)

Also, ANOVA results indicated that there was a significant effect of the complications on the QOL domains of the diabetic non-refugees (control group) as shown in table (36). The F-ratio for the physical domain is (46.05 & Sig. 0.001), for the psychological domain (F 19.74 & Sig. 0.001), for the social domain (F 5.3 & Sig. 0.001), and for the environmental domain (F 10.67 & Sig. 0.001). However, these effects of the complications on the four domains among the controls were less than that of the case group as shown previously in table (34). For example, F-values of the physical and psychological domains among the controls were 46.05 and 19.74 respectively, while for the cases were 95.13 and 64.20 respectively.

**Table (36): The effect of complications on the QOL of the diabetic non-refugees (1<sup>st</sup> control group) by one-way ANOVA**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	49250,09	5	9850,02	46,05	,001
	Within Groups	40848,02	191	213,86		
	Total	90098,12	196			
Psychological domain	Between Groups	22688,95	5	4537,79	19,74	,001
	Within Groups	43889,22	191	229,78		
	Total	66578,17	196			
Social domain	Between Groups	8965,63	5	1793,12	5,39	,001
	Within Groups	63451,53	191	332,20		
	Total	72417,16	196			
Environmental domain	Between Groups	13236,05	5	2647,21	10,67	,001
	Within Groups	47375,92	191	248,04		
	Total	60611,98	196			
Global value	Between Groups	22698,25	5	4539,65	26,25	,001
	Within Groups	33030,69	191	172,93		
	Total	55728,95	196			

( $P < 0.05$ )

By comparing the means of the QOL domains regarding the different complications, we can conclude from table (37) that there was a similar trend between the cases and the controls regarding the way that complications worsened the QOL. However, the main differences between the cases and the controls were in the acuity or the power of that effect. For Example, the refugees with diabetic foot had the mean score 31.42 for the physical domain, 28.50 for the psychological domain, 48.53 for the social domain, 19.9 for the environmental domain, and 29.42 for the global value, while the non-refugees with diabetic foot had the following mean scores 38.50, 53.12, 56.87, 50.87, 48.62 for the physical, psychological, social, environmental, and the global value respectively. Moreover, the total means of QOL for the controls was two-fold better than that of the cases.

**Table (37): The effect of complications on the QOL of the diabetic non-refugees (1<sup>st</sup> control group) by comparison of means**

	Complications of Diabetes		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Diabetic Non-refugees	Retinopathy	Mean	73,50	73,50	66,00	62,75	68,00
		N	16	16	16	16	16
		SD	14,95	17,65	22,06	14,09	14,97
	Nephropathy	Mean	52,78	59,92	64,28	58,07	58,57
		N	14	14	14	14	14
		SD	24,41	16,63	11,86	16,38	16,30
	Neuropathy	Mean	40,90	45,90	50,60	44,00	44,00
		N	10	10	10	10	10
		SD	20,80	24,41	17,40	18,48	20,149
	Diabetic foot	Mean	38,50	53,12	56,87	50,87	48,62
		N	8	8	8	8	8
		SD	12,55	13,01	5,33	12,74	8,56
	Nothing	Mean	75,76	72,06	65,41	64,85	68,99
		N	139	139	139	139	139
		SD	12,78	13,52	18,74	15,51	11,98
	More than one complication	Mean	20,20	32,70	38,20	34,00	28,40
		N	10	10	10	10	10
		SD	15,57	20,56	17,98	19,66	15,69
	Total	Mean	67,84	67,22	62,90	61,01	64,01
		N	197	197	197	197	197
		SD	21,44	18,43	19,22	17,58	16,86

### **8.6.3 Post-Hoc multiple comparisons among the significant differences between the complications of diabetes and the QOL domains among the diabetic refugees and non-refugees by using Scheffe test.**

As shown in the Post Hoc table (Appendix F), the presence of \* in the “Mean Difference” column indicates a significant difference between the variables, and (-) indicates another transformation of the comparison. Obviously, for all of the QOL domains (physical, psychological, social, environmental, and the global value), there were always significant differences between the patients without complications and the patients who had retinopathy, or nephropathy, or neuropathy, or diabetic foot, or more than one complication. On the other hand, significant differences were captured between the patients who had more than one complication and those who had either no complications or only one.

### **8.7 The effect of refuge life on the QOL determinants by Odds ratios**

The odds ratios table (38) showed that the diabetic refugees were more likely to perceive their subjective QOL as poor than the diabetic non-refugees (odds ratio [OR], 7.06; 95% confidence interval [CI], 4.53 – 11.01), more dissatisfied with their general health (OR, 5.8; 95% CI, 3.76 – 8.98), suffering from more pain (OR, 8.4; 95% CI, 5.27 – 13.20), more likely to perceive life as meaningless (OR, 17.6 ; 95% CI, 10.66 – 29.08 ), more likely to feel unsafe in their life, (OR, 9.3 ; 95% CI, 5.20 – 16.70 ), more likely to perceive their physical environment as unhealthy (OR, 11.6 ; 95% CI, 7.02 – 19.45 ), less likely to get health-related information (OR, 10.2; 95% CI, 6.27 – 16.01), more unable to perform ADL (OR, 9.1 ; 95% CI, 5.78 – 14.43), more dissatisfied with self (OR, 11.2 ; 95% CI, 6.95 – 17.93 ), more likely to be dissatisfied with the sexual life (OR, 2.3 ; 95% CI, 1.49 – 3.61), more likely to be dissatisfied with their living place (OR, 17.3 ; 95% CI, 10.45 – 28.55 ), more likely to receive poor health services in the refugee camps (OR, 10.4 ; 95% CI, 6.48 – 16.80), and finally the diabetic refugees were more likely to experience negative feelings such as blue mood, despair, anxiety, depression than the diabetic non-refugees (OR, 8.7 ; 95% CI, 5.49 – 13.63 ).

**Table (38): The most essential variables for probability of low QOL scores related to effect of the refuge life among the diabetic refugees compared with the diabetic non-refugees. The adjusted odds ratios and the 95% confidence intervals (CI) are given.**

<b>Quality of Life determinants</b>	<b>Odds ratios (Diabetic refugees vs. Diabetic non-refugees)</b>	<b>95% Confidence Interval (Upper limit - Lower limit)</b>
1. Rating QOL as poor	7.06	(4.53 – 11.01)
2. Dissatisfaction with health	5.81	(3.76 – 8.98)
3. Suffering from physical pain	8.34	(5.27 – 13.20)
4. Perceiving life as meaningless	17.61	(10.66 – 29.08)
5. Feeling unsafe	9.32	(5.20 – 16.70)
6. Perceiving the physical environment as unhealthy	11.68	(7.02 – 19.45)
7. Lack of health-related information	10.02	(6.27 – 16.01)
8. Physically unable to perform ADL	9.13	(5.78 – 14.43)
9. Self-dissatisfaction	11.16	(6.95 – 17.93)
10. Dissatisfaction with sexual life	2.32	(1.49 – 3.61)
11. Dissatisfaction with living place	17.28	(10.45 – 28.55)
12. Poor quality of health services	10.43	(6.48 – 16.80)
13. Having negative feelings such as blue mood, despair, anxiety, depression	8.65	(5.49 – 13.63)

## Chapter 9

### Results of the study (Part II)

#### **Impact of diabetes mellitus on the QOL of the diabetic refugees**

In chapter 8, the effects of refuge life on the diabetic refugees have been discussed in details. For that purpose, a case group (diabetic refugees) was compared with the first control group, which composed of 197 diabetic patients who live in the cities.

This chapter, on the other side, assesses specifically the effect of diabetes mellitus on the quality of life of the diabetic refugees in Gaza strip by: first, analyzing the demographic data and socio-economic status of the second control group, second, comparing the QOL items of the cases with the items of the second control group of non-diabetic refugees by crosstabulations, and finally conducting comparisons of means and F-test to allocate the significant differences among the groups. Both groups were matched for age, sex and living place.

#### **9.1 Demographic data and socio-economic status of the second control group (non-diabetic refugees).**

The demographic characteristics and socio-economic status of the non-diabetic refugees (table 39) revealed that 53% were males and 47% were females. Age distribution of the diabetic non-refugees shows 33% of the subjects were between the ages of (50-60) years, 25% above 60 years, 11% between the ages of (30-39) years, while 6% less than 30 years old. These sex ratios and age distributions (average 51 years old) were the same in the case and the two control groups in order to control the extraneous variables, thus, minimizing the selection bias. The educational attainment of 2<sup>nd</sup> control group ranged from illiteracy (they did not receive any formal education) to higher educational level. About 4% had no formal school education and are assumed to be illiterate, 4% had only primary school education, 14% and 35% of them had secondary and tertiary school education respectively, while 43% had higher education. Many of the refugees, especially women, were unable to pursue their higher education because of either the financial hardships or the early marriage. Table (39) indicated that most of the subjects in the 2<sup>nd</sup> control group (87%) were married, 3.5% were widowed, 0.05% was divorced and 9% were single at the time of the interview. Like the case and 1<sup>st</sup> control groups, the marriage percentages among the 2<sup>nd</sup> control group subjects were also high; this reflects the tendency of the Palestinian people to

get married earlier and to form a family. The results on the family and household income indicated that the unemployment rate among the non-diabetic refugees was less than that among the diabetic refugees; about 34% of them were unemployed, in comparison with 66% who were employed. However, most of the “employed” refugees work in temporary jobs and gain approximately 200 US\$ or less. As indicated in table (39), the majority of them 51% had a monthly income less than 200 US\$, 42% had an average income 200-500 US\$, and only 7% of them had monthly income more than 500 US\$. In general, these averages fall far below the average income of the non-refugees in the surrounding areas. Regarding the type of the house, 22% of the refugees still live in houses built for them by UNRWA since their displacement in 1948 as the first shelter, while 68% managed to buy or build own houses. However, the houses in the camps are still compacted with each other and lack the basic infrastructure such as roads and sewers. Because many of the non-diabetic refugees still live in extended families, 62% of them had to financially support 0-5 members of their families or relatives, 27% support 6-10 persons and 11% supported more than 10 persons.

**Table (39): Demographic data and socio-economic status of the 2<sup>nd</sup> control group**

<b>Item</b>	<b>Frequency</b>	<b>Percent</b>
<b>Gender</b>		
Male	104	53
Female	93	47
<b>Age in years</b>		
<30	12	6
30-39	21	11
40-49	49	25
50-60	66	33
> 60	49	25
<b>Level of education</b>		
None at all	8	4
Primary school	8	4
Secondary school	27	14
Tertiary school	69	35
Higher education	85	43
<b>Marital status</b>		
Single	17	9
Married	172	87
Widowed	7	3.5
Divorced	1	0.5
<b>House type</b>		
Own	135	68
UNRWA	44	22
Rent	18	10



Continued, table (39)...

<b>Occupation</b>		
Employed	131	66
Unemployed	66	34
<b>Income status per month</b>		
Below 200 US\$	100	51
200-500 US\$	83	42
>500 US\$	14	7
<b>Nr. of persons financially dependent on you</b>		
0-5 persons	122	62
6-10 persons	54	27
>10 persons	21	11

## 9.2 Measuring the differences of quality of life (QOL) items among the case group (diabetic refugees) and the 2<sup>nd</sup> control group (non-diabetic refugees) by crosstabulations

### 9.2.1 Rating quality of life

The diabetic and the non-diabetic refugees were asked to rate their QOL on a scale from very poor to very good. In figure (30), about 65% of the case group reported poor and very poor QOL compared with only 7% of the control group. Among the control group about 69% had rated their QOL as good and very good in comparison with only 17% of the cases. This demonstrated how diabetes had negatively affected HRQOL of the case group.

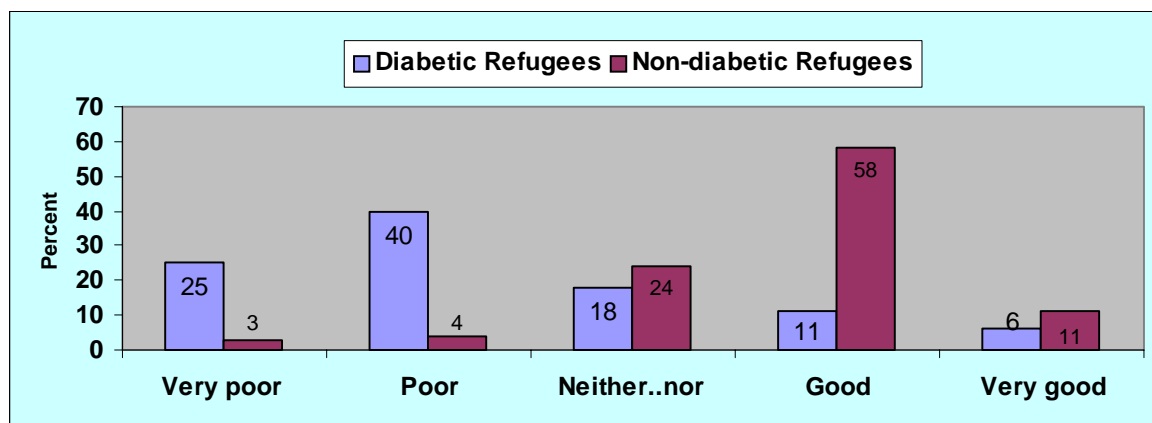


Figure (30): How would you rate your quality of life?

### 9.2.2 Satisfaction with health

Both groups were asked to rate their satisfaction with their health on a scale from very dissatisfied to very satisfied. More than two thirds of the cases were dissatisfied and very dissatisfied with their health, while less than 6% of the controls were so. On the other hand, about 87% of the controls were satisfied and very satisfied in comparison with about 19% of the case group (figure 31).

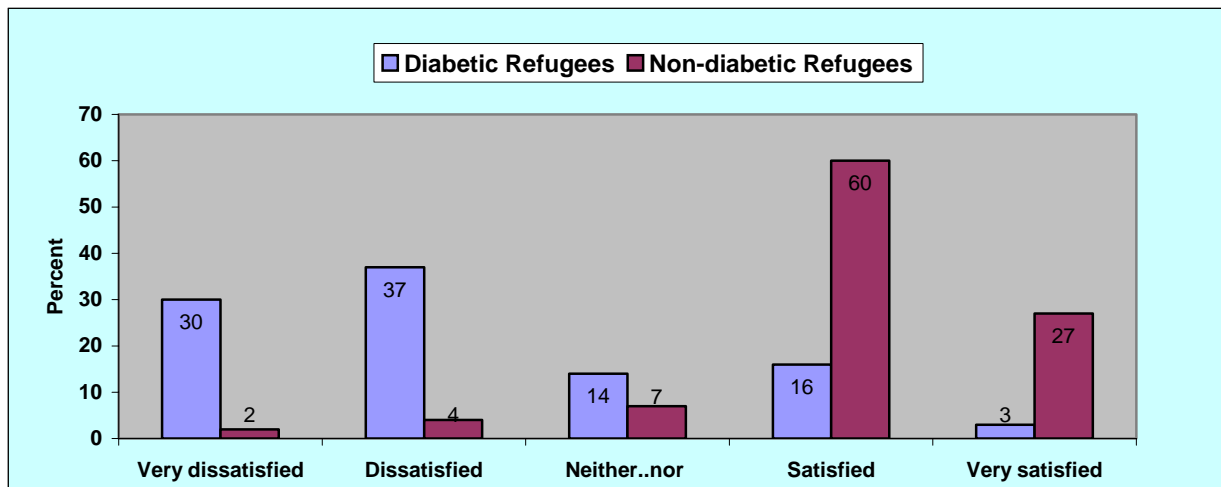
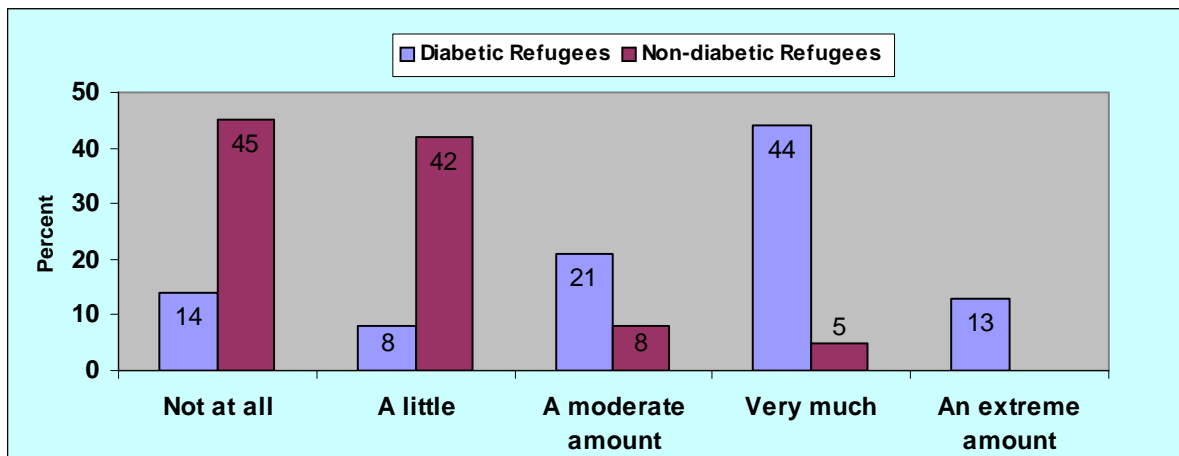


Figure (31): How satisfied are you with your health?

### 9.2.3 Physical pain

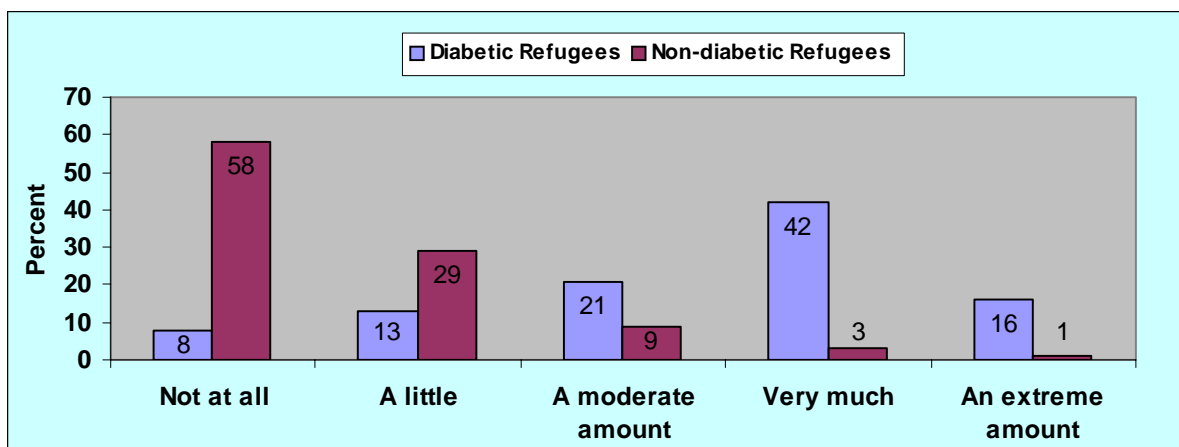
The case and the control groups were asked to rate “to what extent do you feel that physical pain prevents you from doing what you want?” on a scale from not at all to an extreme amount. Figure (32) shows that more than 57% of the case subjects reported that physical pain prevented them from implementing their needs very much to extreme amount while about 5% of the controls reported that pain prevented them very much from doing what they want.



**Figure (32): To what extent do you feel that physical pain prevents you from doing what you need to do?**

#### 9.2.4 Medical treatment to function in daily life

The case and control groups were asked to answer the question “How much do you need any medical treatment to function in your daily life?” on a scale from not at all to extreme amount. About 58% of the case patients reported that they need medical treatment “very much and to extreme amount” in order to be able to function in their daily lives, meanwhile about 87% of the control group did not need any medications or a little (Figure 33).

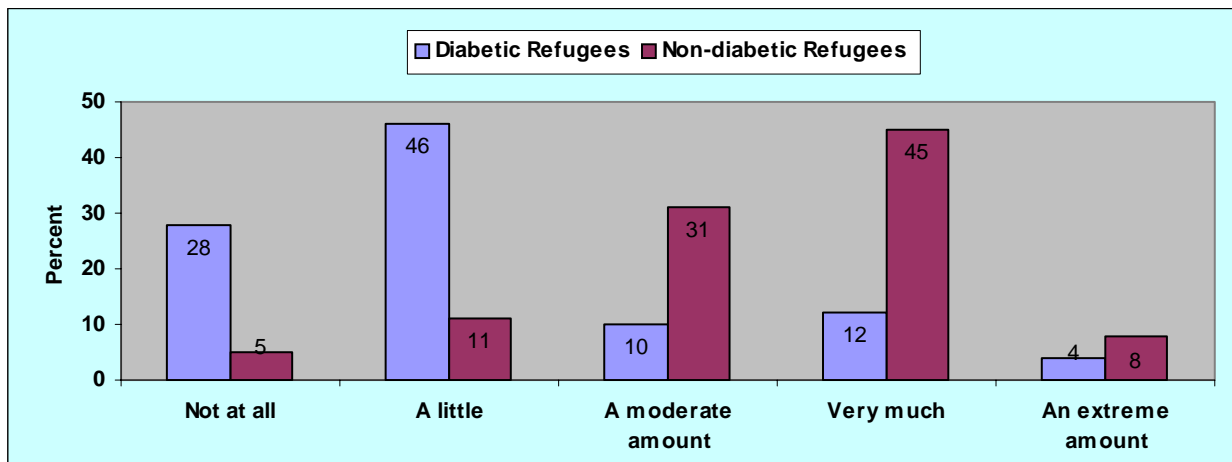


**Figure (33): How much do you need any medical treatment to function in your daily life?**

#### 9.2.5 Enjoying life

The patients were asked to rate “How much do you enjoy life?” on a scale from not at all to an extreme amount. As shown in figure (34), more than 74% of the diabetic refugees answered this question by “a little and not at all”, in comparison with only 16% of the control group. This is due

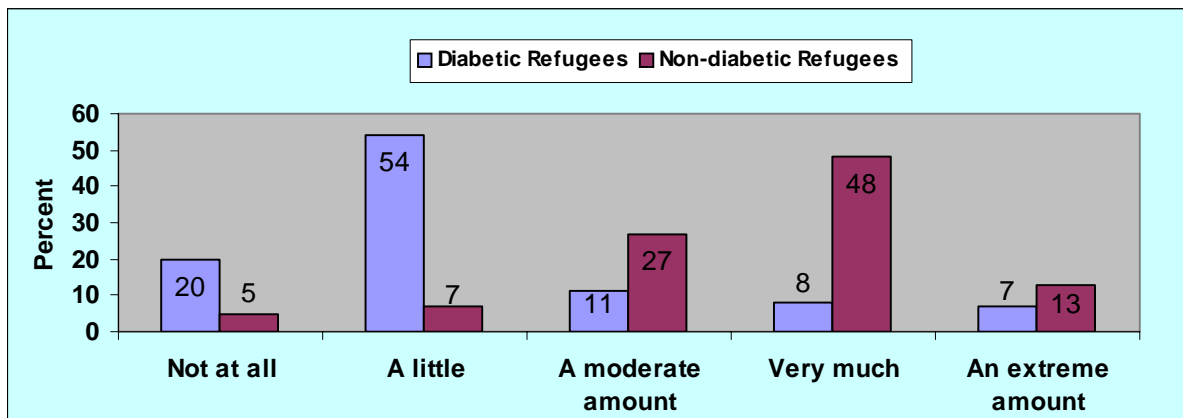
to the diabetes and its consequences. These percentages are congruent with the percentages of diabetic refugees who suffered from diabetic complications. On the other hand, about 53% of the non-diabetic refugees said that they enjoy their life and 31% of them said they enjoy their lives only in a moderate level.



**Figure (34): How much do you enjoy life?**

### 9.2.6 To what extent do you feel your life to be meaningful?

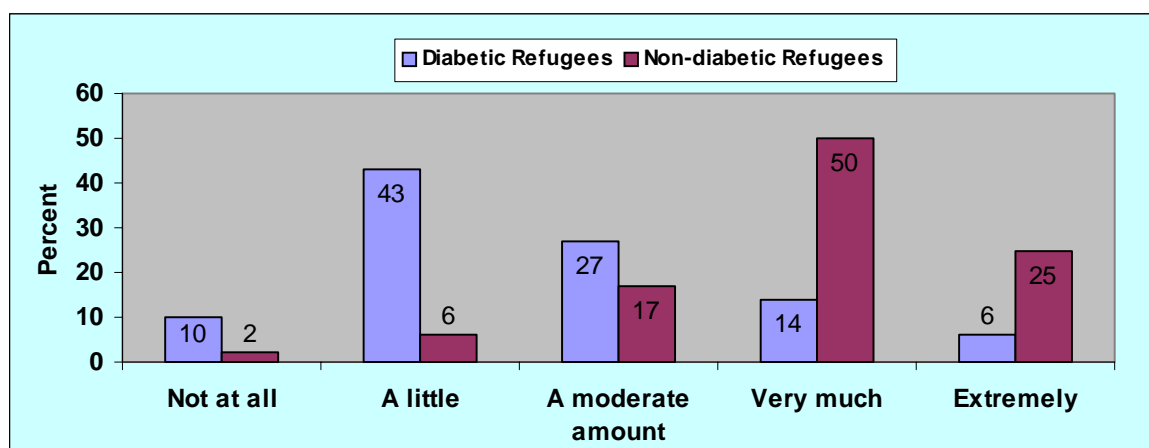
The responses of the case and control groups for this question were rated on a scale from not at all to an extreme amount. According to figure (35), about 74% of the diabetic refugees reported that life has a little meaning or meaningless, while about 61% of the non-diabetic refugees felt that their life is meaningful very much or to an extreme amount. The in-depth information showed that some of them had depressive symptoms like social isolation, others had sexual complications. Some women, especially the singles, had a sense of burden because of the bad perception of the society toward them. A woman reported, “I am now 41 years old and I did not get married because of my disease. No one likes to marry a woman with diabetes”.



**Figure (35): To what extent do you feel your life to be meaningful?**

### 9.2.7 How well are you able to concentrate?

The answers of this question by both groups were rated on a scale from not at all to extremely. The results in figure (36) showed that about 10% of case group reported that they are unable to concentrate at all; more than 43% of them stated that their ability to concentrate is very little; and approximately 27% said that they were able to concentrate moderately. In contrast, about 75% of the control group said that they are able to concentrate very much to an extreme amount.

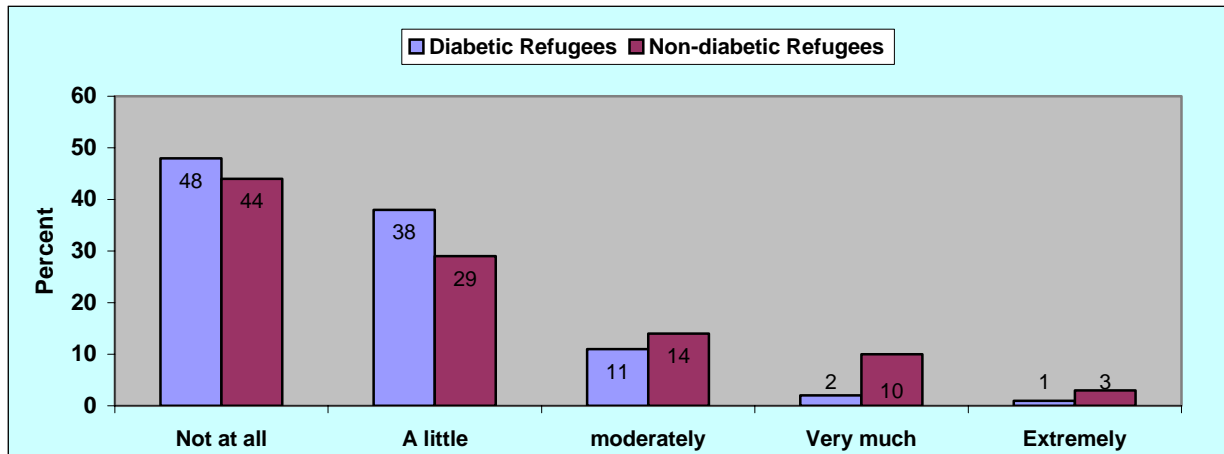


**Figure (36): How well are you able to concentrate?**

### 9.2.8 How safe do you feel in your daily life?

The answers of the cases and controls to this question were rated on a scale from not at all to extremely. As shown in figure (37), about 86% of the diabetic refugees reported no or little safety in their life and about 73% of the non-diabetic refugees reported the same. Obviously, there is no

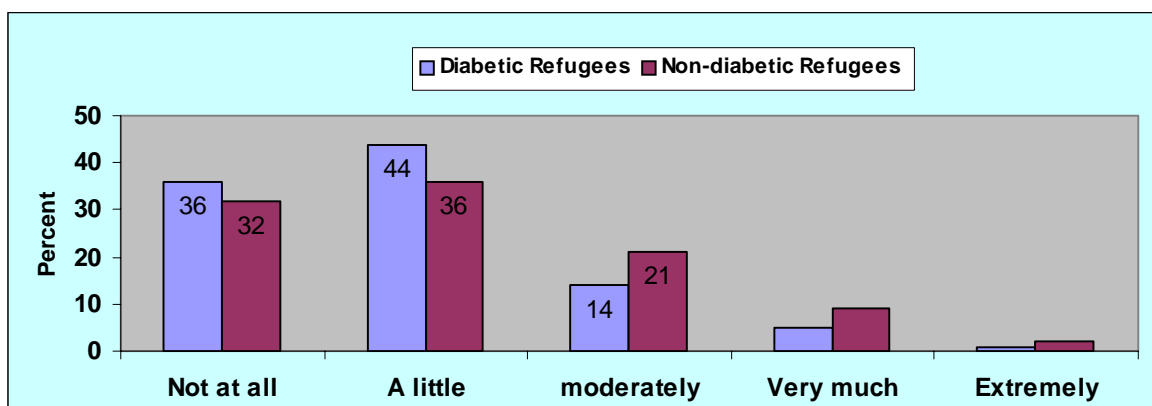
big difference between both groups in feeling unsafe; this is because most of the Palestinians in the refugee camps experience the same hardships and the collective sanctions imposed on them by the occupation. Every day, they witness the Israeli hostilities against their families and homes.



**Figure (37): How safe do you feel in your daily life?**

### 9.2.9 How healthy is your physical environment?

The case and control groups were asked to rate “how healthy is their environment” on a scale from not at all to extremely. According to the results shown in figure (38), 80% of the diabetic refugees have rated their environment as unhealthy in comparison with 68% of the non-diabetic refugees. Also, about 21% of the non-diabetic refugees said that their physical environment was moderately healthy. This means that the majority of the both groups of the refugees were unsatisfied with their physical environment and they perceived it as unhealthy.



**Figure (38): How healthy is your physical environment?**

### 9.2.10 The energy for every day life and the physical health of the diabetic refugees?

This section presents the results of five items of WHOQOL questionnaire together which constitute the physical domain of the global quality of life. These five items or questions were connected with each other to give a full picture of the physical and functional abilities of the diabetic refugees; these items are: energy for every day life, ability to get around, sleep pattern, ability to perform daily living activities, and capacity for work.

Regarding the energy, more than 60% of the diabetic refugees reported not have enough energy for every day life in comparison with only 7% of the non-diabetic. The results of the other aspects of the physical domain showed that 55% of the diabetic refugees suffered from sleep disturbances compared with only 10% of the controls, 62% of the cases reported that their ability to get around was either poor or very poor in comparison with only 13% of the controls, about 65% of the cases were either very dissatisfied or dissatisfied with their abilities to perform the activity of daily living compared with only 9% of the controls, in addition to 69% of diabetic refugees were dissatisfied and very dissatisfied with their capacity to work compared with only 9% of the non-diabetic refugees. According to the previous comparisons, the aspects of the physical domain of the non-diabetic refugees (the 2<sup>nd</sup> control group) were significantly better, which provides another supporting evidence that diabetes mellitus adversely affects most of the physical capabilities of the diabetic refugees.

### 9.2.11 Are you able to accept your bodily appearance?

The results in figure (39) showed that about 14% of the cases had not accepted their body images at all and 35% of them had accepted their bodily appearance a little. Meanwhile, about 81% of the non-diabetics had accepted their bodily appearance mostly and completely.

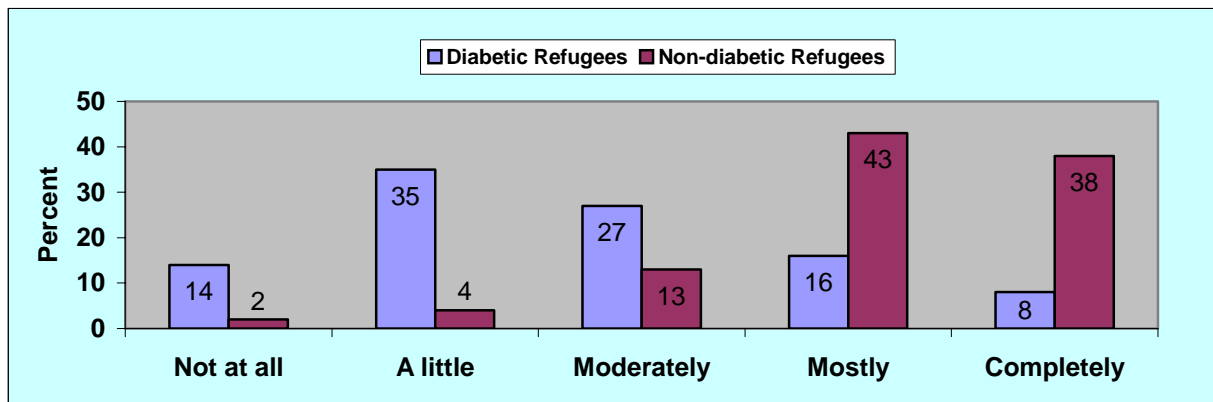


Figure (39): Are you able to accept your bodily appearance?

### 9.2.12 Have you enough money to meet your needs?

As we noticed from the results presented in figure (40), more than 43% of the diabetic refugees reported not having money at all, about 29% had a little money and about 17% had moderately enough money to meet their needs, while only 11% had enough money to support their needs. For the non-diabetics only 36% reported having enough money to meet the basic needs. As we noticed from these results: the majority of the refugees in the camps is poor and lives in very difficult economic situations.

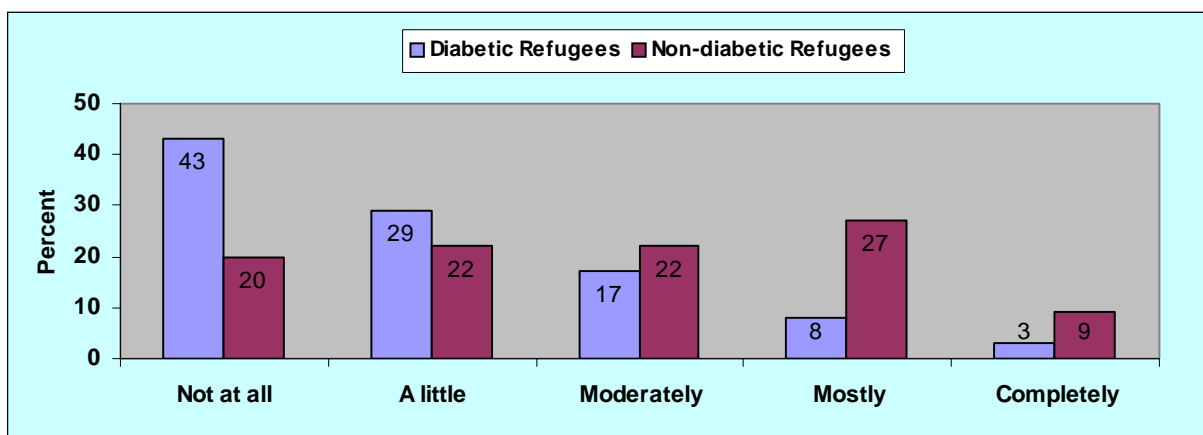
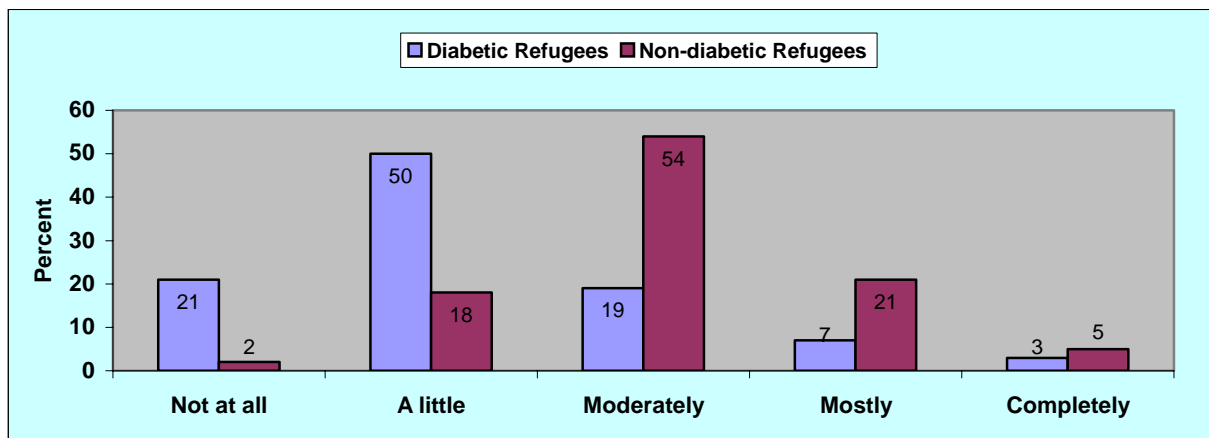


Figure (40): Have you enough money to meet your needs?

### 9.2.13 How available to you is the information that you need in your day-to-day life?

The participants' responses to this question were rated on a scale from not at all to completely. In figure (41), about 71% of the diabetic refugees stated that they could not get enough information in day-to-day life regarding their disease and its management, compared with 20% of the control group. The results also showed that about 54% of the healthy refugees reported having only moderate amount of information regarding the promotion of health and prevention of the diseases. This is a very serious sign that educational measures must be urgently taken to meet the desperate needs for health awareness for all the refugees.

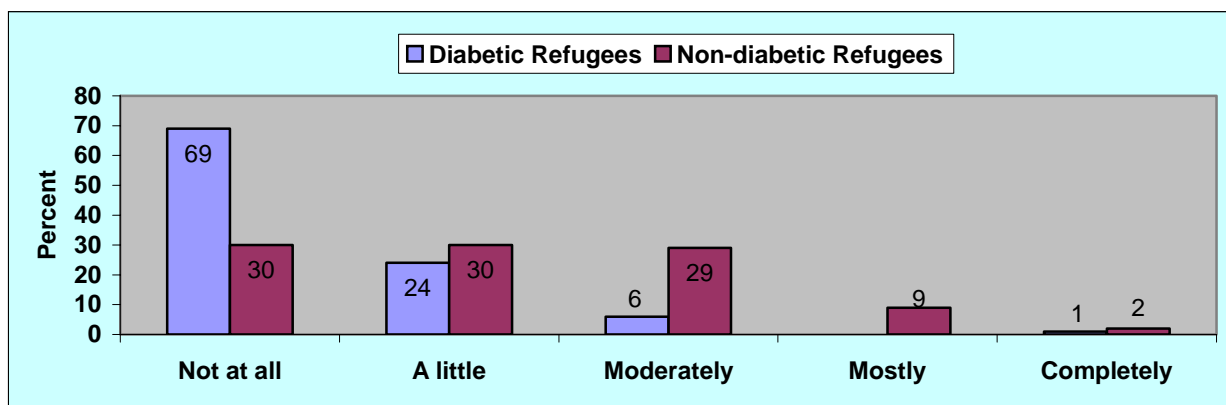




**Figure (41): How available to you is the information that you need in your day-to-day life?**

### 9.2.14 To what extent do you have the opportunity for leisure activities?

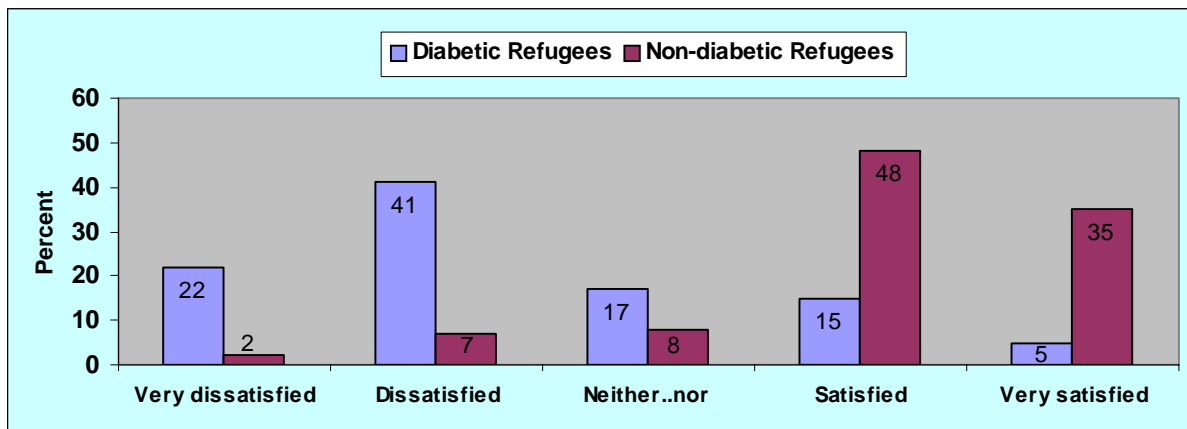
The participants were asked to rate their opportunity for leisure activities on a scale from not at all to completely. The picture that emerged from data on leisure activities is shown in figure (42). About 69% of the case subjects had not at all the opportunity for leisure activities, 24% had only a little and about 6% had moderately the opportunity for leisure activities. For the controls about 60% had no enough chances for the leisure activities.



**Figure (42): To what extent do you have the opportunity for leisure activities?**

### 9.2.15 How satisfied are you with yourself?

The diabetic and non-diabetic refugees were asked to rate the responses for this question on a scale from very dissatisfied to very satisfied. As shown in figure (43), 22% of the diabetic refugees were very dissatisfied and 41% were dissatisfied with themselves, in comparison with only 9% of the non-diabetic refugees. On the other side, only about 20% of the diabetic refugees were satisfied with themselves in comparison with 83% of the non-diabetic refugees.



**Figure (43): How satisfied are you with yourself?**

### **9.2.16 Social life: Satisfaction with personal relationships, the support from friends, and the sexual life**

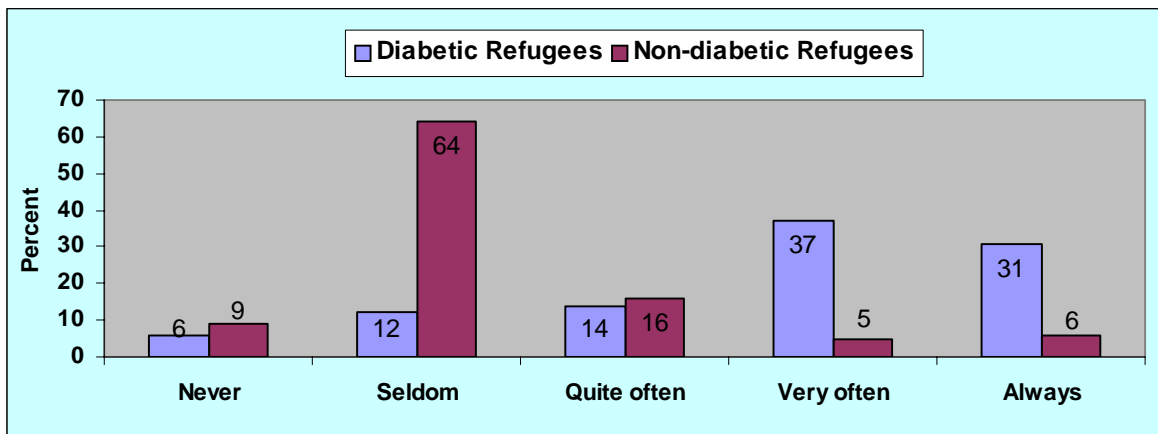
The case and control groups were asked to rate their satisfaction with their personal relationship and the support they get from their friends on a scale from very dissatisfied to very satisfied. These two items in addition to “the sexual life” item constitute the social domain. The majority of the diabetic (68%) and the non-diabetic refugees (84%) were satisfied and very satisfied with their personal relationships. Also, about 71% of the cases and 75% of the controls were satisfied and very satisfied with the support they got from their friends. Regarding the satisfaction with the sexual life, about 73% of the diabetic refugees (cases) were dissatisfied and very dissatisfied with their sexual life in comparison with 48% of the diabetic non-refugees (1<sup>st</sup> control group) and only 13% of the non-diabetic refugees (2<sup>nd</sup> control group).

### **9.2.17 Satisfaction with the living conditions and the transport in the camps**

Both groups were rated their satisfaction with the living conditions and transportations on a scale from very dissatisfied to very satisfied. The responses of both groups of the refugees were approximately the same with no significant differences. For example, more than 78% of the diabetic refugees were dissatisfied with their living conditions in comparison with 65% of the non-diabetic refugees, and about 77% of diabetic refugees were dissatisfied and very dissatisfied with their transport compared with 66% of the non-diabetic refugees.

**9.2.18 How often do you have negative feelings such as blue mood, despair, anxiety, depression?**

The two groups were asked to rate the responses to this item on a scale from never to always. Figure (44) showed that about 82% of the diabetic refugees had negative feelings such as blue mood, despair, anxiety, depression quite often, very often, and always in comparison with only 18% of them said that they had never or seldom experienced such negative feelings. In contrary, about 11% of the control group reported that they never or seldom had such feelings. This indicates that many diabetic refugees suffer from depressive and psychological symptoms, which have a great impact on the individual's functional ability and quality of life.



**Figure (44): How often do you have negative feelings such as blue mood, despair, anxiety, depression?**

### 9.3 Effect of DM on the quality of life domains of the diabetic refugees by comparison of means and analysis of variance (ANOVA)

As shown in table (40), big differences were found among the means of QOL domains of the case group (diabetic refugees) and the 2<sup>nd</sup> control group (non-diabetic refugees). For example, the mean of the physical domain of the cases was 36.69 compared with 75.90 of the controls. Also, the means of the psychological and social domains of the case group were 34.79 and 52.40 respectively, compared with 69.73 and 71.39 of the controls. Moreover, the mean of the global value of the QOL domains for the diabetics was 33.53 while it was 60.84 for the non-diabetics. These results were also confirmed by the analysis of variance among the means of QOL domains for both groups.

**Table (40): Effect of DM on the QOL domains of the case and 2<sup>nd</sup> control groups by comparison of means**

Group		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Diabetic Refugees	Mean	36,69	34,79	52,40	23,43	33,53
	N	197	197	197	197	197
	SD	25,17	24,51	21,06	18,99	20,92
Non-diabetic Refugees	Mean	75,90	69,73	71,39	36,16	60,84
	N	197	197	197	197	197
	SD	15,55	17,61	16,90	16,08	13,38
Total	Mean	56,30	52,26	61,89	29,79	47,19
	N	394	394	394	394	394
	SD	28,67	27,57	21,31	18,69	22,24

As shown in F-test table (41), diabetes mellitus had significant negative impacts on the four QOL domains as well as on the global value of the diabetic refugees. The F-ratio for the QOL domains of the case and control groups were (F 345.99 and Sig. 0.001) for the physical domain, (F 263.90 and Sig. 0.001) for the psychological domain, (F 97.45 and Sig. 0.001) for the social domain, (F 51.59 and Sig. 0.001) for the environmental domain, and (F 238.10 and Sig. 0.001) for the global domain. The strongest effect of DM was located to be on the physical domain (F 345.99), while the weakest effect was found to be on the environmental domain (F 51.59).

**Table (41): Effect of DM on the quality of life domains of the case and 2<sup>nd</sup> control groups by analysis of variance (ANOVA)**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	151460,97	1	151460,97	345,99	,001
	Within Groups	171602,08	392	437,76		
	Total	323063,05	393			
Psychological domain	Between Groups	120242,86	1	120242,86	263,90	,001
	Within Groups	178608,15	392	455,63		
	Total	298851,01	393			
Social domain	Between Groups	35539,50	1	35539,50	97,45	,001
	Within Groups	142948,43	392	364,66		
	Total	178487,93	393			
Environmental domain	Between Groups	15977,36	1	15977,36	51,59	,001
	Within Groups	121395,79	392	309,68		
	Total	137373,16	393			
Global value	Between Groups	73490,25	1	73490,25	238,10	,001
	Within Groups	120990,46	392	308,64		
	Total	194480,72	393			

( $P < 0.005$ )

#### **9.4 Effect of the level of education on the QOL domains of the case and 2<sup>nd</sup> control groups by comparison of means and analysis of variance (ANOVA)**

This section aimed at exploring the effect of the level of education of the participants on the QOL domains. The comparison of means of the different educational levels (table 42) showed that the physical domain of the illiterate subjects was 30.59 in comparison with 54.26 and 70.29 of the subjects who had attained secondary school and higher education respectively. Also the psychological domain reflected the same results: the illiterate participants had a score of 28.68

while the participants who had a tertiary school and higher education achieved better scores of 57.03 and 65.82 for the psychological domain. The global value of the QOL among highly educated participants was 58.8740 compared with only 33.37 and 27.12 for the primary- school educated and illiterate participants respectively.

**Table (42): level of education and quality of life domains of the case and 2<sup>nd</sup> control groups by comparison of means**

Level of education		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
None at all	Mean	30,59	28,68	45,81	16,68	27,1250
	N	64	64	64	64	64
	SD	24,37	24,45	23,05	15,47	18,85
Primary school	Mean	37,64	36,02	55,27	21,97	33,37
	N	37	37	37	37	37
	SD	26,58	23,57	17,17	15,26	19,159
Secondary School	Mean	54,26	49,94	57,21	29,78	45,26
	N	57	57	57	57	57
	SD	26,04	22,84	20,63	18,19	19,22
Tertiary School	Mean	62,49	57,03	65,52	30,59	51,05
	N	109	109	109	109	109
	SD	26,57	26,99	20,23	17,24	20,62
Higher education	Mean	70,29	65,82	70,92	38,00	58,87
	N	127	127	127	127	127
	SD	22,09	22,14	16,68	18,11	17,86
Total	Mean	56,30	52,26	61,89	29,79	47,19
	N	394	394	394	394	394
	SD	28,67	27,57	21,31	18,69	22,24

The previous results shown in the table of the comparison of means were also supported by the following F-test (table 43). This test presented significant effects of the educational level of the participants. The higher the level of education the participant had the better effect on her/his QOL means. This is clearly evident in the ANOVA table below: The F-ratio of the QOL domains of the case and control groups according to the level of education were (F 34.41 and Sig. 0.001) for the physical domain, (F 30.57 and Sig. 0.001) for the psychological domain, (F 20.62 and Sig. 0.001) for the social domain, (F 18.44 and Sig. 0.001) for the environmental domain, and (F 35.49 and Sig. 0.001) for the global domain.

**Table (43): Effect of the level of education on the quality of life domains of the case and 2<sup>nd</sup> control groups by analysis of variance (ANOVA)**

QOL domains		Sum of Squares	df	Mean Square	F	Sig.
Physical domain	Between Groups	84444,66	4	21111,16	34,41	,001
	Within Groups	238618,39	389	613,41		
	Total	323063,05	393			
Psychological domain	Between Groups	71479,41	4	17869,85	30,57	,001
	Within Groups	227371,60	389	584,50		
	Total	298851,01	393			
Social domain	Between Groups	31227,86	4	7806,96	20,62	,001
	Within Groups	147260,07	389	378,56		
	Total	178487,93	393			
Environmental domain	Between Groups	21895,73	4	5473,93	18,44	,001
	Within Groups	115477,42	389	296,85		
	Total	137373,16	393			
Global value	Between Groups	52002,31	4	13000,57	35,49	,001
	Within Groups	142478,40	389	366,26		
	Total	194480,72	393			

( $P < 0.05$ )

### **9.5 Effect of employment status and income status on the quality of life domains of the case and 2<sup>nd</sup> control groups by comparison of means.**

Based on the demographic and economical data of the participants, about 34% of the non-diabetic refugees were unemployed, in comparison with 66% who were employed. By comparing the means of QOL domains among the employed and unemployed subjects (table 44), we found that the scores of the four domains of the employed were higher than the scores of the unemployed. Specifically, the means of physical, psychological, social and environmental domains of the employees were 67.08, 62.27, 68.41, and 36.03 respectively, while these domains among the unemployed were 43.87, 40.72, 54.38, and 22.61 respectively.

**Table (44): Employment status and QOL domains of the case and 2<sup>nd</sup> control groups by comparison of means**

Occupation		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Employed	Mean	67,08	62,27	68,41	36,03	55,92
	N	211	211	211	211	211
	SD	23,79	23,46	17,69	17,72	18,75
Unemployed	Mean	43,87	40,72	54,38	22,61	37,11
	N	183	183	183	183	183
	SD	28,83	27,50	22,66	17,185	21,72

Regarding the income status, there was a positive proportion between the QOL and the income status. In other words, the higher the monthly income, the better the QOL scores (table 45).

**Table (45): Income status and QOL domains of the case and 2<sup>nd</sup> control groups by comparison of means**

Income status		Physical domain	Psychological domain	Social domain	Environmental domain	Global value
Below 200 US\$	Mean	46,13	42,27	55,28	23,17	38,41
	N	229	229	229	229	229
	SD	27,94	26,27	22,32	16,69	20,64
200-500 US\$	Mean	70,50	65,84	70,72	37,30	58,82
	N	132	132	132	132	132
	SD	23,13	22,58	15,68	17,11	18,05
More than 500 US\$	Mean	70,06	67,30	72,48	45,72	61,57
	N	33	33	33	33	33
	SD	23,99	24,95	16,38	17,36	19,60
Total	Mean	56,30	52,26	61,89	29,79	47,19
	N	394	394	394	394	394
	SD	28,67	27,57	21,31	18,69	22,24

## 9.6 The effect of DM on the QOL determinants by Odds ratios

The odds ratios table (46) showed that the diabetic refugees were more likely to perceive their subjective QOL as poor than the non-diabetic refugees (odds ratio [OR], 12.3; 95% confidence interval [CI], 7.62 – 19.83 ), more dissatisfied with their general health (OR, 27.7; 95% CI, 15.54 – 49.47), suffering from more physical pain (OR, 21.2; 95% CI, 11.96 – 37.38), more likely not



to enjoy life (OR, 8.8; 95% CI, 5.52 – 13.86), more likely to perceive life as meaningless, (OR, 11.5 ; 95% CI, 7.16 – 18.42), less likely to have enough energy for everyday life (OR, 19.5; 95% CI, 11.44 – 33.34), more likely to have body image disturbances (OR, 11.9; 95% CI, 7.15 – 20.05 ), less likely to get health-related information (OR, 4.7 ; 95% CI, 2.98 – 7.34), more unable to physically get around (OR, 11.5; 95% CI, 7.16 – 18.60), reported more sleep disturbances (OR, 9.9; 95% CI, 6.08 – 16.05), more unable to perform ADL (OR, 18.3; 95% CI, 10.90 – 30.85), more dissatisfied with self (OR, 17.3; 95% CI, 10.28 – 29.17), more likely to be dissatisfied with the sexual life (OR, 13.2; 95% CI, 8.18 – 21.38), and finally the diabetic refugees were more likely to experience negative feelings such as blue mood, despair, anxiety, depression than the diabetic non-refugees (OR, 12.9; 95% CI, 8.03 – 21.00).

**Table (46): The most essential variables for probability of low QOL scores related to effect of DM among the diabetic refugees compared with the non-diabetic refugees. The adjusted odds ratios and the 95% confidence intervals (CI) are given.**

<b>Quality of Life determinants</b>	<b>Odds ratios (Diabetic refugees vs. Non-diabetic refugees)</b>	<b>95% Confidence Interval (Upper limit - Lower limit)</b>
1. Rating QOL as poor	12.30	(7.62 – 19.83)
2. Dissatisfaction with health	27.73	(15.54 – 49.47)
3. Suffering from physical pain	21.15	(11.96 – 37.38)
4. Not enjoying life	8.75	(5.52 – 13.86)
5. Perceiving life as meaningless	11.49	(7.16 – 18.42)
6. Not having enough energy for everyday life	19.53	(11.44 – 33.34)
7. Poor perception of body appearance	11.98	(7.15 – 20.05)
8. Lack of health-related information	4.67	(2.98 – 7.34)
9. Physical disability to get around	11.54	(7.16 – 18.60)
10. Sleep disturbance	9.87	(6.08 – 16.05)
11. Physical disability to perform ADL	18.33	(10.90 – 30.85)
12. Self dissatisfaction	17.32	(10.28 – 29.17)
13. Dissatisfaction with sexual life	13.23	(8.18 – 21.38)
14. Having negative feelings such as blue mood, despair, anxiety, depression	12.98	(8.03 – 21.00)

## **Chapter 10**

### **Discussion**

This comparative quantitative-qualitative study examined how diabetes mellitus and the refugee life conditions affected the quality of life of the diabetic refugees in the refugee camps in Gaza strip in comparison with other two control groups: the diabetic non-refugees and the non-diabetic refugees. Data were obtained using in-depth interviews and WHOQOL-BREF questionnaire in a complementary way to ensure the comprehensiveness of the collected data.

This chapter presents a summary and discussion of the major findings of this study highlighting the deep suffering of the chronically diabetic patients under the refugees' conditions and the scarcity of the health resources.

#### **10.1 Demographic data and health profile of the Palestinian diabetic refugees and non-refugees**

The demographic statistics of this study showed that the age of most of the diabetic refugees were more than 40 years old (83%) while only 6% were less than 30 years old. About 43% of them were either illiterate or had only primary school education. This could be attributed to the difficult life conditions they faced during and after exodus in 1948 and the lack of educational resources in the refugee camps between 1948 and 1967. Many of the refugees, especially women, were unable to pursue their higher education because of the financial hardships and/or the early marriage. Many diabetic refugees still live in extended families including married children, siblings, in-laws and first degree relatives staying with the family in the same house, this indicates that the refugees are overloaded not only with their personal costs but also with the costs of other family members who are economically dependent on them, which negatively affect their ability to manage their illness, thus, negatively affect their quality of lives. It is noted from table (15) that the marriage percentages among the groups are high and almost the same, this reflects a cultural characteristic of the Palestinian community which encourages the young people to get married and form a family. About 60% of the refugees were unemployed. They suffer from a difficult financial hardship and depend mostly on the aids and relieves delivered to them from UNRWA and other non-governmental humanitarian organizations. Since the beginning of Al-aqsa Uprising, most of the refugee workers lost their works in Israel, which created additional

difficulties for them to cover their basic daily life expenses. In general, 90% of the refugees reported either no income or less than 500 US\$. These averages fall far below the average income of the non-refugees in the surrounding areas. The crowdedness as well as the lack of enough supplies and facilities had affected the physical (e.g., more at risk, diseases), psychological (e.g., stress, fears, hopelessness), social (e.g., refugee status, roles), and mental health of the refugees. As a result, the impact of the refuge situation on QOL of the diabetic refugees was more intensified and worse than it would be on other individuals such as the non-diabetic refugees and the diabetic non-refugees.

The health profile of the diabetic refugees showed that most of them (92%) suffered from Type 2 diabetes while only 8% had Type 1. These percentages are almost comparable to the prevalence of both types of diabetes in the Palestinian population as indicated by the annual report of the MOH (MOH, Annual report 2003). The duration of diabetes ranged from 1 year to more than 10 years. However, many of them had been diagnosed as a result of the presence of one or more diabetic complications, such as diabetic foot, visual impairment, etc. This indicated the importance of the public education regarding the regular health check-up and the recognition of the early symptoms of diabetes. Surprisingly, the percentage of refugees with complications of diabetes was very high (80%) in comparison with non-refugees (29%) and more than 32% of the refugees reported having more than one complication.

The participants reported different types of treatment as indicated in table (22). About 24% of the diabetic refugees were on insulin therapy; about 54% were on oral hypoglycemic agents (OHAs). These percentages are still higher than the desired optimal range of 25% according to the literature. Only 7% was exclusively managed by lifestyle modification such as diet control. The results in this study are approximately congruent with the MOH annual report (2003). According to this report, the distribution of cases by management showed that about 20.0% of all diabetics were managed by insulin treatment, about 30.0% were treated with a combined therapy (insulin and OHA), and about 45.0% treated with oral anti-diabetic agents and only 5.0% was exclusively managed by lifestyle modification such as diet control.

In theory, 50% of the diabetics should be treated by dietary management, weight reduction and physical exercise. This indicated how huge the gap is between what is desired and what having been achieved for the Palestinian refugees with diabetes.

## **10.2 Measuring the effect of the refuge life on the quality of life of the diabetic refugees by descriptive statistics and crosstabulations (differences in QOL among the case and 1<sup>st</sup> control group)**

This part presents clear evidences that the refuge life negatively affected the QOL of the diabetic refugees in comparison with the diabetic non-refugees who live in the cities in Gaza Strip.

Figure (4) showed that about two thirds of the diabetic refugees reported poor and very poor QOL compared with only 11% of the control group. These percentages indicated that the Palestinian diabetic refugees, in addition to disease process that they are going through, are deprived of certain social and economic benefits. The status of "refugee" itself has become a chronic condition that impacts their daily life. This indicated that the QOL of the Palestinian refugees in general and the diabetics in particular continues to spiral downward in response to ongoing hardships, suppression and the frequent curfews and seize. This led to difficulties for the diabetic refugees to reach the hospitals and medical centers to receive their needed health care, which in turn negatively affected their QOL.

Regarding satisfaction with health, figure (5) showed that more than two thirds of the cases were dissatisfied and very dissatisfied with their health, while less than 15% of the controls were so. In Gaza strip, refugees with diabetes suffer from shortages of comprehensive health care and community resources. This influence diabetes-related knowledge, communication with providers, ability to adhere to recommended medication, exercise, and dietary regimens, and treatment choices. According to these results, there is considerable evidence that the refugee environment and its consequences adversely affected the health of the diabetic refugees. The Palestinian diabetic refugee patients are unable to carry out the required management of consistency in meals and medications and they do not have enough resources, motivation and willingness to fulfill management and control objectives, which may contribute to other diseases and further decreased function. A study done by Sundquist (1995) showed that the Latin American immigrants in Scandinavian countries were most vulnerable and all immigrants or refugees had increased self-rated poor health compared with Swedes.

Regarding the physical pain, figure (6) showed that more than 57% of the refugees reported that physical pain prevented them from performing their needs very much to extreme amount while about 14% of the diabetic non-refugees reported so. The status of the Palestinian refugees in

Gaza strip with diabetes and the characteristics of their camps or neighborhoods led to poorer quality of care and worse self-care behaviors. These results are supported by the percentage of the refugees who complaint of diabetic complications (80%), because the more complications the patient has, the more physical pain he suffers from. In another population-based study, Smith (2004) found that general health among American diabetics was lower and diabetes associated with pain statistically compromised every dimension of QOL such as physical health, mental health, limited activity, rest or sleep, and energy.

Figure (7) showed that about 79% of the refugees reported that they need medical treatment in order to be able to function in their daily lives, and only 8% of said that they manage diabetes with diet and weight reduction. It is observed from the health profile of the participants that a high percentage of the refugees depend completely on the medications (e.g., insulin, OHAs, or both) to control their diabetes rather than on the preventive measures such as lifestyle modifications, weight reduction, physical exercise, and etc. This highlights the importance of the systematic health education programs for the diabetic refugees to assist them to increase their knowledge and to change their perception about the diabetes and its treatment.

Regarding enjoying life, figure (8) showed that more than 74% of the diabetic refugees do not enjoy their lives, in comparison with only 13% of the control group. Since the beginning of Al-Aqsa Uprising in late September 2000, the Palestinian refugees in the refugee camps in Gaza strip especially who live near the Jewish settlements, have been suffering from multifaceted difficulties that include: restrictions on movement, frequent curfews, the increasingly pervasive and deepening poverty, the growing number of house demolitions, increasing unmet psychosocial needs, and the obstacles faced by humanitarian workers. In addition to this, many of them are suffering from diabetic complications, which diminished the ability to get around and enjoying their life. On the other hand, about 67% of the diabetic non-refugees said that they enjoy their life. This could be, first, related to the lower incidence of the complications and physical pain; and, second, related to the better living conditions in the cities like Gaza compared with the camps. But still there were about 33% of the non-refugees who reported that they did not enjoy life, mainly because they live in the southern cities in Gaza strip (such as Rafah) that experienced severe punishing measures from the occupation.

Figure (9) showed that about 74% of the diabetic refugees reported that life has a little meaning or meaningless, while about 73% of the diabetic non-refugees felt that their life is meaningful. Smith (2004) confirmed in his population-based study that lower education, being unable to work, unemployed, or retired and lacking funds to pay for needed medical care were associated with greater impairments among persons with diabetes. The Palestinian diabetic refugees who perceived their life as meaningless have experienced diabetic complications, hardships of the life, insufficient amount of medications, and deepening poverty. Moreover, bad societal perception of the diabetic patients was also a major concern especially among the females. Some unmarried women stated that diabetes was the major obstacle for them to get married; others said that they had fear that their husbands will divorce them or get married from another “healthy” woman. This showed the desperate need to increase the health awareness not only of the diabetic refugees and their family members but also of the community as a whole. For those 26% of the diabetic refugees who still feel that their life is meaningful, this is mainly due to the religious values and faith in God, which necessitate that the person must always be satisfied with the disease and with his life conditions. Many of them consider their disease as an exam from God, and they were satisfied with God’s will. They believe that their faith in God brought them inner tranquility and solace amidst all the day-to-day suffering.

Regarding the ability to concentrate, figure (10) showed that about 53% of the refugees reported concentration disturbances. The hard life of the refugees, the deteriorated health status and the presence of diabetic complications diminished the ability of mental concentration among the refugees. Also, the fluctuation of hypoglycemia and hyperglycemia negatively affected the functions of the brain and the ability of concentration. In a very interesting study to assess the effect of hypoglycemia on attention and intelligence of the humans, McAulay et al. (2001) found that during hypoglycemia, attentional flexibility deteriorated and speed of information processing was delayed but the intelligence scores did not deteriorate during hypoglycemia.

Figure (11) showed that about 86% of the refugees reported no or little safety in their life and about 79% of the non-refugees felt little to moderately safe in their daily life. It is observed that the majority of both groups feel unsafe in their daily life because of the unstable political situation in Gaza strip. These results are supported by studies conducted in the occupied Palestinian territory by the U.S and Swedish Save the Children, which indicated that the

psychological well being of Palestinian Children is under significant strain due to the omnipresence of violence in their surroundings and the resulting pervasive feeling of danger. Almost half of the children (48 per cent) have personally experienced violence owing to the ongoing conflict or have witnessed an incident of such violence befalling on immediate family member. Nine of ten parents report symptomatic traumatic behavior amongst their children, ranging from nightmares and bedwetting, to increased aggressiveness and hyperactivity, as well as a decrease in attention span and concentration capacity (Save the Children, 2003; UNRWA, 2003).

Regarding the healthiness of the physical environment, figure (12) showed that 80% of the diabetic refugees have rated their environment as unhealthy in comparison with only 20% of the non-refugees who live in the cities. Accordingly, there are observable differences in life styles and living conditions among the urban and the refugee camp communities. Gaza strip, in general, is a very crowded place and the refugee camps have one of the highest population densities in the world. The spatial concentration of refugees in settlement camps, shanty towns or slums is often associated with high risks of disease epidemics because of the overcrowding in areas with poor provision of infrastructural facilities such as piped water and health care facilities. Transportation contributes also to the air pollution in the camps related to high density of traffic and the high number of old cars. Surprisingly, 80% of the non-refugees perceive their physical environment as healthy, mainly due to the bigger and well-ventilated houses, which connected with healthy sewage networks, surfaced roads, and the availability of governmental and non-governmental health care institutions.

The results regarding the energy for every day life (figure 13) showed that approximately 60% of the diabetic refugees reported that they either did not have energy at all or only a little amount for every day life; meanwhile, only 13% of the diabetic non-refugees did so. Fluctuations of the blood glucose levels, presence of diabetic complications in high percentages (e.g., amputated legs, nephropathy, neuropathy, etc.) in addition to the presence of diabetes-associated depression led to the depletion of the energy needed to carry out the daily activities among the diabetic refugees. In contrary, 67% of the non-refugees had mostly and completely enough energy to normally function in their daily life in comparison with only 16% of the case group. This indicates how the refuge life with its unaffordable conditions adversely affects the diabetes management and resulted in insufficient energy for them to normally pursue their lives.

Regarding the satisfaction with body image, figure (14) showed that about 49% of the cases had not accepted their bodily appearance at all or a little. Those refugee patients can be classified into three groups: first, the obese women; second, the patients who already had complications especially the amputated limb and neuropathy which distorted the general appearance and the coordination of the body. The third group, which reported poor perception of the body appearance, was the insulin-dependent who were underweight and whose skin was damaged as a result of frequent injections and blood sampling. But still there are a relatively large number of the refugees (24%) who accepted their body appearance in spite of the complications. This could be attributed to religious values and faith in God, as they refer every thing happened for them in the life as an exam from God and they must successfully pass this exam by accepting their inner suffering in return for the reward they expected to have in this and the other life.

Figure (15) showed more than 72% of the refugees reported not having enough money to support their needs in comparison with 41% of the non-refugees. Curfews and closures imposed on Gaza strip by the Israeli military have hit the camps hard, since the majority of the refugees are largely dependent on income from work inside Israel. As a result, unemployment has risen and socio-economic conditions in the camps have deteriorated further. There are generally inadequate jobs, and socio-economic conditions in the camps are generally poor. These results are completely congruent with the statistics presented in table (18) regarding the monthly income of the refugees. These statistics showed that the majority of them (65%) had no monthly income or less than 200 US\$ and 22% of the diabetic refugees had an average income 200-500 US\$, these averages fall far below the average incomes of the non-refugees in the surrounding areas. These statistics are consistent with another study conducted and published by the World Bank which indicated that 72% of the Palestinian refugees live below a poverty line of \$3.60 a day (Overall, 72 percent of Palestinians live below a poverty line of \$3.60 a day (Fowler, 2004). The only thing that alleviated the financial hardships of the refugees was the international aids donated by the European Union, UNRWA, Japan, and other international institutions.

The results regarding the availability of the information were amazing. Figure (16) showed about 71% of the refugees stated that they could not get enough information in day-to-day life regarding their disease and its management. Most of them did not know the etiological factors of the disease and the best way to manage it. This may be attributed to the crowdedness in the



clinics of the UNRWA and the MOH in the camps (huge numbers of patients and few health personnel). Thus, the refugee patients had a very restricted time span to talk to the doctors in the clinics which led to not receiving enough instructions and education to manage their disease. In addition, our media (TV, Radio, Newspapers, etc.) mostly focus on the political situation rather than on the health educations for those who suffer from chronic diseases.

Regarding the opportunity for leisure activities, the assumption is that the more varied and numerous leisure activities, the better quality of life. But the picture here is different: Figure (17) showed that 93% of the refugees had not at all or a little the opportunity for leisure activities. This is because the camps are not well facilitated, in terms of leisure activities and programs. The principle constraints listed by refugee men were lack of facilities, complications, work, and lack of money. The main obstacle to participation in leisure activities listed by women, in addition to the complications, were lack of facilities, restraints imposed by social conventions, and child care. Only 1% of the refugees had mostly or completely the opportunity for the recreational activities in comparison to about 37% of the non-refugees. The main leisure activities of the refugees were hobbies, enjoying nature and, not surprisingly, a religious study group, in which religious texts are discussed in the mosques, at least once weekly. In short, the majority of the refugees expressed dissatisfaction with their inability to take part in leisure activities they find meaningful.

Figure (18) showed that about 62% of the cases reported that their ability to get around was either poor or very poor, in comparison to 15% of the controls. As the diabetic refugees stated, the main reason for the restriction of their movements was the long-term complications of diabetes, such as blindness, dialysis, symptomatic neuropathy, foot ulcers, amputation, stroke, and congestive heart failure. These complications were associated with more substantial reductions in their ability to get around, consequently, led to worse health-related quality of life. These results were supported by a study done by Tucker (2000) who found that patients with diabetes are two to three times more likely to report disability than their non-diabetic counterparts.

Regarding satisfaction with sleep, figure (19) showed that about 55% of the diabetic refugees suffered from sleep disturbances and there were unsatisfied with their sleep pattern. This could be referred to the current unsafe situation in and around the camps. Almost every night, the camps

especially those located near the Israeli settlements, were susceptible to fire exchange, military incursions and missile attacks, which interfered with quiet sleeping. For the diabetics in particular, sleep disturbance is possibly caused by impaired glucose metabolism or physical and psychological discomfort due to the disorder. According to the literature, uncontrolled diabetes is associated with signs of depression which mostly leads to insomnia, this fact applied also to the refugees. Many of the diabetic refugees reported that they had to wake up several times in the night to urinate (polyuria), which disturbed the sleeping pattern. In addition, many of the diabetic refugees suffer from pain and discomfort as shown in figure (6), as we know that pain severely inhibits the normal pattern of sleeping. Interestingly, the literature indicates also that not only uncontrolled diabetes results in sleep disturbances but also sleep disturbances themselves in middle-aged men, are associated with an increased risk of diabetes (Nilsson et al., 2004).

Figure (20) showed that about 65% of the case group were very dissatisfied and dissatisfied with their abilities to perform the activity of daily living. These results were expected because of the high number of the Palestinian diabetic refugees who suffer from physical pain (57%), diabetes related complications (78%), sleep disturbances (55%), and diminished energy for daily life (60%). All of these factors interfere with the ability of the diabetic refugees to perform their daily living activities as they wish. These findings are completely consistent with a recent study done by Wu et al. (2003). This study showed that, presence of diabetes and associated complications might lead to a significant decline in functional status among these patients. In contrary, the majority of the control group was satisfied with their ability to perform daily living activities. This might be attributed to the low incidence of the complications and the associated pain, controlled blood glucose level, and normal sleep pattern.

Figure (21) showed that more than 69% of the case group was either dissatisfied or very dissatisfied with their capacity to work. This percentage is consistent with the percentage of the unemployed refugees (table 17) and the average monthly income of them (table 18). Inability to work and loss of independence were ultimately the greatest concern for many of the diabetic refugees. The majority of them are poor and they have to work to earn money to feed their extended families. But, the hazards of the disease and associated complications especially physical and functional disability declined their energy and capacity to work. This in turn led to reduced productivity, diminished QOL, and an increase in the economic burden for these individuals and the Palestinian society at large.

Figure (22) showed that 22% of the diabetic refugees were very dissatisfied and 41% were dissatisfied with themselves, in comparison with only 11% of the diabetic non-refugees. Most of the diabetic refugees in the refugee camps were not satisfied with their capacity for work, had sleep disturbance, suffered from physical pain and complications, and had no leisure activities. The normal consequence for all of these negative aspects was loss of self-satisfaction. On the other hand, about 36% of the cases were relatively satisfied with themselves although some of them experienced many difficulties with the disease. This could be referred to the religious values and the strong faith in God.

Interestingly, figures (24) and (25) shows approximately similar results related to the social domain. The majority of the case and the control groups (more than 70%) were satisfied and very satisfied with their personal relationships and with the support they got from their friends. As we know that the Palestinian community, like all Arab communities, is a very conservative one and its members try always to maintain a cohesive adherence with each other and build durable relationships with the family members, neighbors, and other friends; for example, if one of them face a crises, the others hurry up to support him not only psychologically but financially as well. Regarding family and children, most of the participants from both groups emphasized the importance of the harmonious family relations that assure secure house, love and understanding. They also voiced the importance of family as a support system and its role in giving a sense of closeness and 'home' or shelter for the human being. Regarding the social life in general, many of the diabetic refugees and non-refugees explained that having social relations meant to have neutral and good relations with relatives, neighbors and friends within the limits accepted by the social beliefs system. Mostly, they informally visit each other, and participate in other formal happy or sad occasions such as weddings, graduation, childbirth, death and sickness. They also attached sharing and caring about neighbors, as emphasized by their religion to give meaning to social life and relations.

Figure (25) showed that about 73% of the diabetic refugees were dissatisfied and very dissatisfied with their sexual life and more than 48% of the diabetic non-refugees were so. The assumption hypothesized by the investigator regarding the sexual life of diabetics was: diabetes causes sexual dysfunctions for both the refugees and non-refugees with a higher rate among the refugees because of the uncontrolled blood glucose level. These results confirmed this assumption. The

differences in the prevalence between the case and the control groups might be attributed to the increased complications, physical pain, and psychological distress among the refugees. Although this issue was very sensitive to deeply talk about during the interviews, but after indirect and probing questions, diabetic men expressed their concern regarding erectile dysfunction, and diabetic women reported that the arousal phase is predominantly affected. These results are in a full agreement with most of the literature which indicate that diabetic men and women are at greater risk of developing sexual problems which associated with reduced quality of life.

Figure (26) showed that more than 78% of the diabetic refugees were extremely dissatisfied with their living conditions. For the diabetic non-refugees who live in the cities, about 68% were satisfied and very satisfied with their living conditions. These results are completely compatible with the results presented in figure (12) regarding the physical environment (80% of the diabetic refugees has rated their environment as unhealthy in comparison with only 20% of the non-refugees who live in the cities). Since the establishment of the refugee camps in Gaza strip by UNRWA in 1948, the socio-economic conditions are generally poor with a high population density, cramped living conditions and inadequate basic infrastructure such as roads and sewers. For example, over 76,000 refugees live in Beach camp (on the west of Gaza city) whose area is less than one square kilometer. Most of them reside in small shelters with inadequate infrastructure. The poorly furnished rooms have uneven floors, unpainted or cracked concrete walls and roofs, some made of metal sheeting with poor ventilation. Poor living and housing conditions (sometimes more than 15 persons live in one small house), coupled with extremely high rates of unemployment and little access to high quality of health, make the diabetic refugees some of the most disadvantaged populations in the world.

Figure (27) showed that most of the diabetic refugees (77%) were dissatisfied and very dissatisfied with their transport. This was due to inability of the refugees to have own cars and they must use the public transportation (mainly taxis), however a large proportion of the vehicles used as taxis are not qualified to operate as public vehicles. Moreover, the roads inside and outside the camps, with the exception of a few main roads are not frequently maintained and are in relatively poor condition. Also, the current insecure situation has exacerbated the suffering of the refugees; since January 2001, the Israeli occupation forces have frequently closed the two main roads that connect the camps with the cities. As a result of this internal closure, the

Palestinian refugees were not permitted to reach health facilities, schools, workplaces, fields, family members and homes that lie in another area of the partitioned Gaza Strip. Regarding the non-refugees, about 41% of them were satisfied and 11% were very satisfied with their transportation; this is mainly related to the better economic situation and their ability to buy private cars. In addition, they mostly did not need to travel outside the cities (like the refugees) to get the medical or health care because almost each city has one hospital.

Figure (28) showed that about 82% of the diabetic refugees had negative feelings such as blue mood, despair, anxiety, depression quite often, very often, and always. This indicates that many diabetic refugees suffer from depressive and psychological symptoms, which have a great impact on the individual's functional ability and quality of life, which in turn impair adherence to medical treatment and glycemic control, and increases the risk of more and more diabetes complications.

### **10.3 The effect of refuge life and other demographic factors on the QOL domains of the diabetic refugees by comparison of means and one-way ANOVA test.**

Regarding the effect of refuge life on QOL, table (24) and ANOVA output table (25) show strong and significant differences in the QOL domains between the diabetic refugees and non-refugees. The most significant difference was found in the environmental domain, then the psychological domain, then the physical domain, whilst the least significance was in the social domain because every one of the refugees feels that s/he is obliged to carry out her/his social responsibilities even though their health status is difficult. Moreover, the overall difference in the global value between the two groups was highly significant as indicated by the F ratio: 253.40 with a significant level: 0.001. These results supported the findings in section 8.3.9 where 80% of the diabetic refugees have rated their environment as unhealthy in comparison with only 20% of the non-refugees. Undoubtedly, it is concluded that living in a camp and having diabetes has had a real negative effect on the QOL (dependent variable), thus, rejecting the null hypothesis, which indicates no effect. These results are compatible with other few studies conducted on the QOL of the refugees regardless of their health status. For example, in a study conducted to evaluate whether female Bosnian refugees have a poorer quality of life than Swedish women, the results showed 38% of Bosnian refugee women irrespective of health status had lower quality of life in

'appetite', 'memory', 'leisure time', and aspects of mental well-being such as 'energy', 'patience', 'sleep', 'mood', and 'health' in comparison with only 23% of the Swedish women (Sundquist et al., 1998). Another study (Younis et al., 2003) conducted in Iraq to assess the impact of war and sanctions on the QOL of the population. It is found that the quality of life is poor in Iraq, with the effects being greatest in the region worst affected by war.

Pertaining the age and QOL, tables (26 & 27) showed that all of the quality of life domains of the diabetic refugees were affected by the aging process but in different levels. The impact of old age on the physical domain was severe, while the social domain had the better QOL mean scores (58.41) and there were no huge differences between the highest and the lowest mean scores within the different age groups. As we previously mentioned, the Palestinian community is a conservative one and its members try always to maintain a cohesive adherence with each other and build durable relationships with the family members, neighbors, and other friends. The environmental domain had the lowest mean (16.44), because the environmental factors that the refugees experienced affected all the refugees regardless of their age group. This conclusion was also verified in the post hoc comparisons (Appendix D). For the diabetic non-refugees there was only a mild impact of the age on the QOL. This is because the diabetic non-refugees had better access to health care than the refugees, which led to better possibility to control their disease and to prevent the physical complication. In summary, there was a significant effect of the aging process on the QOL of the diabetic refugees especially on the physical and psychological domains, while for the non-refugees the effect of the age on the QOL was mild but not significant. These results partially agreed with the study of Redekop et al. (2002) and with the findings reported by Rubin and Peyrot (1999). They found that older age is always associated with a lower HRQOL.

Regarding the gender and QOL, tables (28 & 29) indicate that the males had significantly better QOL domains than the females and the control females scored better global value of the QOL than case females. Based on the qualitative inductive analysis, many of the single diabetic females in the case group expressed their concern regarding their chances to get married. They stated that the main obstacle for them to get married was having diabetes. The married females also reported their anxiety and fear from becoming divorced or separated from their spouses because of the diabetes and its complications. A lot of them stated that getting pregnant while

having diabetes is a matter of life or death either for the baby or for the mother because of the pregnancy-associated complications for the diabetics. Moreover, the man-dominated society in which the diabetic females live, have to stay most of the time at home under the authoritative power of their men. Many of them quit education because of the early marriage while others did so because of multi-pregnancies. In conclusion, mean quality of life in males and females among the case group is less than the control group in both sexes at all domains. Overall, the total quality of life means among males in the case and control group at all domains is higher than the total quality of life means among females in both groups. We can immediately conclude a rejection of null hypothesis and an acceptance of the alternative hypothesis, which indicated the presence of an effect of the gender on the QOL domains. These results correspond remarkably well with the findings reported by Rubin and Peyrot (1999), who systematically analyzed all recent literature on diabetes and quality of life and with a study conducted by Redekop et al. (2002) to estimate the health-related quality of life (HRQOL) and treatment satisfaction for patients with type 2 diabetes in the Netherlands and to examine which patient characteristics are associated with quality of life and treatment satisfaction, it is found that female sex, insulin therapy, presence of complications, longer duration of diabetes, and obesity were associated with a lower HRQOL.

Regarding the effect of the type of diabetes on the QOL, as we can observe from the table (30) that the means of the QOL domains for Type 1 diabetics were slightly better than those for Type 2. However, these differences among the means were not so big to reach a significant effect and the slight improvement in QOL for Type 1 diabetics may be attributed to the young age of the subjects (mostly younger than 40 years) and most of them have not yet developed any diabetes-related complications. The ANOVA table (31) also indicated no significant differences between the means of QOL domains of Type 1 and Type 2 diabetics; thus, the null hypothesis is accepted which indicates no effect. These results are in conflict with most of the studies conducted to find the connection between type of diabetes and QOL. For example, Jacobson and colleagues found that Type 2 patients not taking insulin reported higher QOL than Type 2 patients taking insulin. Type 2 patients on insulin still experienced better HRQOL than type 1 patients. For the Palestinian refugees, however, the type of diabetes did not affect the QOL because the main concern is the accessibility of health care and the healthy environment around.

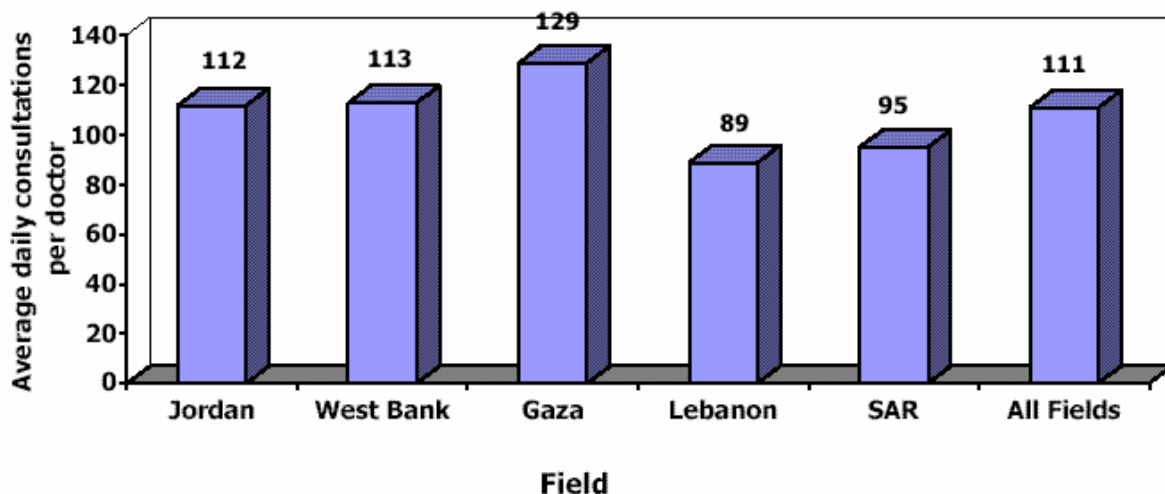
Regarding the duration of diabetes and QOL: The results shown in table (32) represented a very interesting phenomenon. Directly after diagnosis, the patients suffered from, what is so-called, psychological shock and they were not able to accept or adapt to the new situation (as if they enter the denial stage); this is why their QOL values decreased in the first year of diagnosis. But after 2-5 years, they started to psychologically accept their disease and manage it correctly (as if they move in bargaining stage), as a result, their QOL means improved. Finally, when diabetes extends to more than 10 years and the patients started to develop complications and/or comorbidities, their QOL domains significantly decreased. These results correspond remarkably well with the findings reported by several previous studies; a study (Hart et al., 2003) conducted to investigate the health-related quality of life of patients with newly diagnosed type 1 diabetes in the first year after diagnosis and to compare their health-related quality of life, 1 year after diagnosis, with people of comparable age from the general population, revealed that, although health-related quality of life is initially decreased when the diagnosis of type 1 diabetes is made, after 1 year, health-related quality of life was comparable with that of subjects in the general population. In another study conducted by Redekop et al. (2002) to estimate the health-related quality of life (HRQOL) and treatment satisfaction for patients with type 2 diabetes in the Netherlands, it is found that older age, presence of complications, and longer duration of diabetes were associated with a lower HRQOL.

In this table, it is also worthy to observe that the psychological domain of newly diagnosed refugees was low (39.53) compared with the social and physical domains (55.00 and 41.40 respectively), because they had not yet develop any complications, but after 10 years of having diabetes, the physical and psychological domains were the same but low. This is not surprising, because complications and comorbidities are the primary determinant of HRQOL in patients with diabetes, and complications are unlikely to develop within 1 year of the early diagnosis of diabetes. On the other hand, Rubin and Peyrot (1999) reported that several studies found that increased duration of diabetes was associated with decreased QOL, while some have found no significant association between QOL and disease duration.



#### 10.4 Comparison between the health services provided by the Palestinian Ministry of Health (PMOH) and by UNRWA for the diabetic patients in Gaza Strip.

According to figure (29) and the qualitative analysis, the majority of the diabetic refugees (78%) were not satisfied with the health care provided by the UNRWA centers in the refugee camps in Gaza strip. The major source of their dissatisfaction was the crowdedness of the clinics and the disproportionate number of health personnel to the number of clients. The presence of only one doctor per shift is very problematic, this forces the doctor to hurry up and try to finish without providing a good quality of care. These findings are in agreement with the UNRWA report (2003). According to this report, the workloads at UNRWA health centers continued to be high with an Agency-wide average of 111 consultations per medical officer per day compared to an average of 99 in 2003. Similar to previous years, the highest workload was reported from Gaza strip and the West Bank, 129 and 113 respectively (figure 45). This steady increase in the average daily workload of medical officers was mainly due to the increased demand on UNRWA medical care services owing to the generalized socio-economic hardship and the consequences of the ongoing humanitarian crisis in the occupied Palestinian territories. These heavy workloads continued to be reason for concern with regard to maintaining the quality of services.



**Figure (45): Average daily workloads per doctor in all UNRWA fields of operations**

( Source: UNRWA, 2003)

This excessive work overload in the clinics led to the absence of a comprehensive physical examination for the diabetic refugees and ineffective therapeutic communication among the

health staff and the clients. The relationship between the doctor and the patients is very stressful, in which the patients expected to receive a relatively good care and to be handled respectfully. The doctors, on the other side, do not have enough time to spend with every client because of the exhausted number of patients who are waiting outside. One patient said: “never ever any doctor examined me. He writes the prescription before I finish talking”. She criticized the way doctors handled the patients and not giving them the freedom to express their feelings. Another source of dissatisfaction of the refugees with the UNRWA health services was the lack of specialist (diabetologist) in the clinics. They thought “a general doctor is not enough; we need to be examined by diabetologist at least once every month”. Another concern was the lack of information they received from the health personnel in the clinics. They had not received sufficient information about the disease and how to deal with their illness. Therefore, many of them do not know what to do when they were under severe hypoglycemia or hyperglycemia. Most of the diabetic refugees who participated in this study desperately need information about their disease, its course and treatment in order to help them manage their disease effectively; those refugees had questions concerning the etiology, diagnosis, pathophysiology, and symptomatology of the disease. Insufficient information threatens one’s ability to accurately appraise and handle a situation. Another huge gap of information was detected regarding the medication. Clearly, most of them did not understand or appreciate the side effects of an insulin overdose or skipping a dose for some days. They lack information about insulin and its administration as the dose, the sites of injection, the importance of rotating the sites, and food intake after injection. As a result of such information deficiency, many of them, especially the illiterate, developed cultural misconceptions about the disease and its management. For example, many of them used to manage diabetes by traditional recipes or Arabic medicine besides insulin. These findings of not having enough information regarding their disease are in agreement with results in the section 8.3.13 when the refugees were asked to rate “How available to you is the information that you need in your day-to-day life?” on a scale from not at all to completely. About 71% of the refugees stated that they could not get enough information in day-to-day life regarding their disease and its management.

On the other hand, about 11% of the diabetic refugees were either satisfied or very satisfied with the health care provided in the UNRWA clinics. This was mostly because of the free-of-charge medication. Most of the refugees had no health insurance and they cannot afford the costs of the private doctors or buy the medications from the pharmacies. Instead, they prefer to wait long

hours in the clinics to be examined at no cost by the general doctors and to get free-of charge medications.

Regarding the health services of the PMOH, more than the half (55%) of the clients expressed their satisfaction with MOH care especially in Gaza city. Mostly because of the adequate and regular care they received either in the clinics or at the hospitals. In Rimal diabetic clinic in Gaza city, for example, there were two days every week for the diabetics to come for check-up and physical examinations. A highly qualified staff, composed of community nurses, doctors and social workers, are always available to offer consultations and health care for the diabetics. Any case needs more follow-ups will be directly referred to the emergency department at Al-Shefa hospital or to the outpatient diabetic clinic there.

Moreover, regular educational sessions were held for the patients in the clinics, which provided a sense of satisfactions for the patients who became more able to understand their disease and to manage its undesired consequences. The relationship between the patients and the staff seemed to be transparent and confident which let the diabetics to feel safe in dealing with their disease. In spite of the crowdedness there, the health team tried their best to provide a high quality of care. According to a study done by Abu Mousa (1998) to assess the diabetes mellitus problem in Gaza Strip, the blood glucose of patients registered at MOH centers (51%) is more controlled than those registered at UNRWA (61%). Regarding specialist consultations, 80.8% of the UNRWA's patients did not consult the specialist during the last six months, in comparison with only 34.5% of the MOH's patients. This indicated that patients registered at MOH centers have better chance to have consultation by specialist more than patients registered at UNRWA centers, This is due to specialists from the hospital are running the main MOH health Center: Rimal Center. Regarding the appointment system for patients' visits, UNRWA technical instructions of NCDs management recommend interval for next appointment for diabetic patients by three months for majority of patients. At MOH health centers the patients are requested to come every two weeks. In summary, existing diabetes care services are less than the needs of patients. Blood chemistry investigations and data reporting are not adequate; consultations by specialists and appropriate comprehensive services have not yet satisfied the patients. Upgrading professionals' skills specially for staff running the NCD clinics through in-service training by specialists in different aspects of diabetes and its complications, and availability of needed medications in due time are very essential to improve the NCD control and prevention program including DM control program.

## **10.5 The impacts of diabetes-related complications on the QOL domains among the diabetic refugees and the diabetic non-refugees in Gaza strip.**

As we mentioned in 8.2.4, the percentages of refugees with complications of diabetes in this study was very high (about 80% of the cases) in comparison with non-refugees (about 29% of the controls). Interestingly, more than 32% of the refugees reported having more than one complication and only 20% did not have any complication. In contrast, only 5% of the non-refugees reported having more than one complication and 71% had no complications.

According to many studies, the complications are major predictor for the lower quality of life of the diabetics. In this study, we found very clear significant effects of the different diabetes-related complications on the QOL domains. **For the diabetic refugees**, three comparisons have been observed in table (35). First, it is found that the patients who did not develop any complication had better means of the QOL domains than those who had only one complication. Second, patients without complications had better QOL mean scores than those patients who suffered from more than one complication. Third, the diabetic refugees who had one complication achieved higher QOL scores than those who suffered from more than one complication. This means that the patients who had more than one complication had worse QOL than those who had only one and so on. Thus, we can symbolize this finding in the following equation:

(QOL without complications > QOL one complication > QOL more than one complication).

This indicated that diabetic complications (blindness, dialysis, symptomatic neuropathy, foot ulcers, amputation, stroke, and congestive heart failure) were associated with more substantial reductions not only in the physical abilities of the refugees but also in their psychological wellness. These results correspond remarkably well with the findings reported by Rubin and Peyrot (1999), who systematically analyzed all recent literature on diabetes and quality of life. In their meta-analysis study, Rubin & Peyrot found that complications of diabetes, particularly the presence of two or more complications, are the most important disease-specific determinant of QOL and associated with worsened QOL.

The total mean of the social domain remains the best one in comparison with the other domains. Patients who suffered from visual impairment (retinopathy) and diabetic foot considered the physical environment very bad, this is may be related to the lack of surfaced roads and special traffic lights services in the streets to help the visually impaired diabetics to reach their targets safely.

**For the diabetic non-refugees,** ANOVA results also indicated that there was a significant effect of the complications on the QOL domains of the diabetic non-refugees (control group) as shown in table (36). However, these effects of the complications on the four domains among the controls were less than that of the case group. This is, obviously, related to the refugee environment and its consequences. The health care that the patient receives is inadequate, stress level is higher than that of regular individuals, leisure activities may be absent, etc. The diabetic refugees encounter additional problems in dealing with diabetes that affects every aspect of their life. They are unable to carry out the required management of consistency in meals and medications because they do not have enough resources, motivation and willingness to fulfill management and control objectives. According to the study conducted by Abu Mousa (1998), (48.5%) of the patients registered at UNRWA clinics have not been examined for retinopathy, although 30.3% of them have been diagnosed before 10 years. According to the last blood glucose readings reported at the patients' files, 60.3 % of them were considered to have uncontrolled blood glucose. UNRWA technical instructions of NCDs management recommend interval for next appointment for diabetic patients by three months for majority of patients, while at MOH health centers the patients are requested to come every two weeks. In summary, most of the diabetic refugees suffer from at least one diabetic complication, which associated with worse health-related quality of life.

**For both groups,** we can conclude from (tables 35 & 37) that there was a similar trend between the cases and the controls regarding the way that complications worsened the QOL. However, the main differences between the cases and the controls were in the acuity or the power of that effect. Such positive aspects of the diabetics who live in the cities could be attributed to the better quality and quantity of health services available for them in comparison to their counterparts who live in the camps. The adequacy of the health care in the cities (e.g., Gaza city) definitely helps prevent the occurrence of the complications or retard its progress.

## **10.6 Impact of diabetes mellitus on the QOL by descriptive statistics and crosstabulations (differences in QOL among the case and 2<sup>nd</sup> control groups)**

Initial rating of the QOL in figure (30) showed that about 65% of the case group reported poor and very poor QOL compared with only 7% of the control group. This demonstrated how diabetes had negatively affected HRQOL of the case group. As we know that diabetes is considered one of the most physically and psychologically demanding of the chronic medical illnesses because it can compromise physical function (e.g., development of complications), psychological status (e.g., depression), and social relationships (e.g., interpersonal conflict). The burden and difficulty felt by the diabetics in adhering to therapeutic regime, as well as the conflict between having to carry out social roles and the necessity to sustain self-management behavior have been revealed to have a great influence on the diabetic refugees' quality of life. In a study to determine the relationship between mental disorders and diabetes in a representative community sample, Kruse et al. (2003) found that, overall levels of psychiatric comorbidity were higher in diabetic patients than in the general population sample.

Regarding the satisfaction with health, figure (31) showed that more than two thirds of the cases were dissatisfied and very dissatisfied with their health, while less than 6% of the controls were so. In Gaza strip, refugees with diabetes in the camps were dissatisfied with their health because of the deficiency in the health services they received. As indicated elsewhere in this study, about 78% of the diabetic refugees were dissatisfied with the health services provided for them in the camps. They lack diabetes-related knowledge, good communications with providers, ability to adhere to recommended medication, exercise, and dietary regimens, and treatment choices. So, they were at increased risk of cardiovascular, peripheral vascular and cerebrovascular disease. The natural progression of the disease to nephropathy and retinopathy led to renal failure and blindness. The consequences of cardiovascular disease and neuropathy resulted in early cardiovascular death, foot disease and amputation. Many of the diabetic refugees suffer from not only physical complications but also cognitive disabilities. In addition to the traditional vascular complications, diabetes has been associated with excess risk for cognitive and physical decline, falls, fractures, and depression. These complications, which are common among the Palestinian diabetic refugees can profoundly affect quality of life, will challenge clinicians, Palestinian health care system, and public health organizations to identify effective ways of optimizing quality of life among the refugees with diabetes.

Regarding the physical pain and medical treatment, more than 57% of the case subjects reported that physical pain prevented them from implementing their needs very much to extreme amount (figure 32) compared with only 5% of the non-diabetics. In a cohort study done by Krein et al. (2005), it is found that approximately 60% of diabetic subjects reported chronic pain, which was a major limiting factor in the performance of self-care behaviors that are important for minimizing diabetes-related complications. This indicated how much the disease process and its complications (especially diabetic neuropathy) caused discomfort and pain for the diabetic refugees, which affected their body functions and interfere with their abilities to pursue normal life. This is why about 58% of the case patients reported that they need medical treatment “very much and to extreme amount” in order to be able to function in their daily lives (figure 33).

Figure (34) showed that more than 74% of the diabetic refugees do not enjoy their lives in comparison with only 16% of the control group. This is due to the diabetes and its consequences as 80% of the diabetic refugees participants were suffering from complications and more than 32% of them reported having more than one complication which diminished the ability to get around and enjoying the life. According to the qualitative inductive analysis, most of the diabetic refugees expressed their worries and fears of their unknown future with diabetes. They believe that every diabetic patient must develop, sooner or later, one or more complications. They have a perception that the life expectancy for the diabetics is short because of the complications. Because of their knowledge deficiency, the minority of them believes that most of the diabetic-related complications are preventable and the diabetic people can pursue a normal life like the others if acceptable blood glucose level is maintained.

According to the meaning of the life, figure (35) showed that about 74% of the diabetic refugees reported that life has a little meaning or meaningless, while about 61% of the non-diabetic refugees felt that their life is meaningful very much or to an extreme amount. This indicated that DM could also affect the spiritual life of the diabetic refugees. The refugees with diabetes felt that they were different from the others, because they have to fulfill many of the obligations every day. They have to monitor their blood sugar regularly; they are not allowed to eat or drink every thing like normal people; and they are always susceptible to develop short-term and long-term diabetic complications. Accordingly, some of them showed depressive symptoms like social isolation, others had sexual complications like erectile dysfunctions. Some women, especially the

singles, had a sense of burden because of the bad perception of the society toward them. All of these physical and psychological consequences made their lives unenjoyable.

The question of “ability to concentrate” showed that about 53% of case group reported concentration disturbances in comparison with only 25% of the control group (figure 36). Basically, neurocognitive deficits (e.g., inability to concentrate) have been observed in adults with type 1 diabetes, particularly those with at least five episodes of severe hypoglycemia and in patients with peripheral neuropathy. Among older adults with type 2 diabetes, cognitive deficits have been reported in association with poor glycemic control (Rubin & Peyrot, 1999). These results are in harmony with the findings of several studies: Asimakopoulou and Hampson (2002) who reviewed the evidence for deficits in cognitive functioning in older people with diabetes and consider the implications for diabetes self-management. They found that Type 2 diabetes has been associated with an increased risk of developing dementia or Alzheimer’s disease. Other large prospective studies (Leibson et al., 1997; Ott et al., 1999) have provided strong evidence that older people with diabetes are at a significantly higher risk of developing all types of dementia and Alzheimer’s disease. From these evidences and others, it is concluded that diabetes increases the risk of developing serious cognitive impairment such as dementia or Alzheimer’s disease, which adversely affect the QOL.

Regarding feeling safe in the daily life, figure (37) showed that most of refugees regardless of their health status reported no or little safety in their life. This is because most of the Palestinians in the refugee camps experience the same hardships and the collective sanctions imposed on them by the occupation. Every day, they witness the Israeli hostilities against their families, homes and lands. A study conducted by the Gaza Community Mental Health Programme (GCMHP, 2001) on the prevalence of post-trauma stress disorders (PTSD) among children 10-19 years of age revealed that 32.7 per cent reported feeling unsafe and suffered from acute level of PTSD which needed psychological intervention, 49.2 per cent suffered from moderate PTSD symptoms, 15.6 per cent of the children suffered from low level of PTSD and 2.5 per cent had no symptoms. It also indicated that children who are living in camps suffer more than children who are living in towns (84.1 per cent and 15.8 per cent respectively). These findings are alarming.

Evaluating the physical environment by the participants showed that the majority of the diabetic



and non-diabetic refugees have rated their physical environment as unhealthy (figure 38). As we know that the refugees live in eight very-crowded camps in Gaza strip. These camps suffered from lack of sanitation resources, unhealthy sewage system, and poor-ventilated houses. The health services in the camps are inadequate and not comprehensive (as evident in section 8.5). The hospitals are concentrated only in the big cities. Moreover, the polluted air and the scarce water resources exacerbated the conditions of the refugees. All of these factors and others led to the deterioration of the environmental conditions in the camps and the quality of life of the refugees especially the diabetics.

Regarding the energy and the physical domain, more than 60% of the diabetic refugees reported that they either did not have energy at all or only a little amount for every day life, in comparison with only 7% of the non-diabetic refugees. These results presented a clear evidence of how this chronic disease depleted the energy of the patients, which in turn negatively affected the other aspects of the physical domain. Regarding the other aspects of the physical domain, the results showed that the majority of the diabetic refugees suffered from sleep disturbances, poor ability to get around, and dissatisfaction with their capacity to work and their abilities to perform the activity of daily living. Meanwhile, the aspects of the physical domain of the non-diabetic refugees (the 2<sup>nd</sup> control group) were significantly better, which provides another supporting evidence that diabetes mellitus adversely affects most of the physical capabilities of the diabetic refugees. Fluctuations of the blood glucose levels, presence of diabetic complications in high percentages (e.g., amputated legs, nephropathy, neuropathy, etc.) in addition to the presence of diabetes-associated depression led to the depletion of the energy needed to get around and carry out the daily activities among the diabetic refugees. This may result in a "cycle of disability" with progressive deconditioning and loss of independence. As a result, more overloads were added on the family members to assist their relatives in performing such activities. These results were supported by a study done by Tucker (2000) who found that patients with diabetes are two to three times more likely to report disability than their non-diabetic counterparts.

Perception of body image results showed that about 49% of the diabetic refugees had not accepted their body images in comparison with only 19% of the non-diabetics (figure 39). As we know that obesity is a major independent risk factor for the development of type 2 diabetes and is associated with the rapid increase in the prevalence of type 2 diabetes. Many of the case group subjects were obese ( $BMI > 30 \text{ kg/m}^2$ ) especially among Type 2 patients. According to the

available statistics, the reported proportion of diabetic patients with obesity was 58.3% (42.3% in males and 69.3% in females) in Al Remal health center (MOH Annual report 2003). Considering the importance of diet in the management of type 1 diabetes, it is believed that patients with this disease are at an increased risk for body image disturbances and developing eating disorders, specifically anorexia nervosa and bulimia nervosa (Ward et al., 1995). However, the literature has been inconclusive, with some studies demonstrating a higher prevalence of eating disorders in patients with type 1 diabetes and other studies reporting no difference between those with and without type 1 diabetes (Meltzer et al., 2001). Others reported that presence of complications particularly the amputated limb and neuropathy had severely interfered with perceiving a good body image. Moreover, using insulin frequently and rotating the injection sites caused a partial damage of the skin, which distorted the body appearance especially for females.

Figure (40) showed that more than 72% of the diabetic refugees do not have enough money to meet the basic needs. As we noticed from these results that the majority of the refugees in the camps are poor and live in very difficult economic situations. The reasons for that fall into two categories; the first one is general and common among all the refugees regardless of their health status such as the deteriorated political situation in the occupied land and the high unemployment rate. The second category is specific for the diabetics whose capacity for work was diminished as a result of the presence of physical complications and the uncontrolled glucose levels. These statistics are consistent with another study conducted and published by the World Bank, which indicated that 72% of the Palestinian refugees live in pervasive and deepening poverty (Fowler 2004).

Regarding the availability of the information for the daily life, figure (41) showed that about 71% of the diabetic refugees stated that they could not get enough information in day-to-day life regarding their disease and its management. Most of diabetics in the camps lack information and knowledge regarding their disease and the best way to manage it. The results also showed that about 54% of the healthy refugees reported having only moderate amount of information regarding the promotion of health and prevention of the diseases. This is a very serious sign that educational measures must be urgently taken to meet the desperate needs for health awareness for all the refugees.

Regarding opportunity for leisure activities, figure (42) indicated that most of the diabetic and non-diabetic refugees had not at all or a little opportunity for leisure activities. Lack of facilities,

complications, work, lack of money, restraints imposed by social conventions, and child care were the major constraints set by the participants to take part in the leisure activities.

The results of self-satisfaction item, as shown in figure (43), indicated that 63% of the diabetic refugees were very dissatisfied and dissatisfied with themselves, in comparison with only 9% of the non-diabetic refugees. This is attributed to the diabetes mellitus and its life-threatening complications. Large percentage of the case group suffers from physical and functional disabilities which prevented them from being productive and active members in the society. As a result, many of them developed depressive symptomatology like a feeling of powerlessness and hopelessness. As the investigator observed in the interviews, many of the case subjects characterized by weak beliefs in their self-efficacy and a pessimistic outlook on life because of the false perceptions about the disease and its consequences. Many recent studies have shown that people with diabetes have twofold-increased odds of depression compared with individuals without diabetes (Egede, 2004). According to Guthrie et al. (2003), the psychosocial impact of diabetes is ubiquitous and involves the patient and the entire family. They often experience the classic stages of grief, progressing from anger and denial to bargaining, depression, and finally resolution or acceptance. Unresolved grief leads to families becoming dysfunctional if they were not already so.

Interestingly, the results in the social domain (subsection 9.2.10) for the 2<sup>nd</sup> control group were similar to the results for the 1<sup>st</sup> control and the case groups. Almost every member in the Palestinian community, regardless of his health status, tries always to maintain a cohesive adherence with each other and build durable relationships with the family members, neighbors, and other friends. But, it is worthy here to mention that the non-diabetic refugees showed slightly better satisfaction within the social domain, as they are physically more able to implement the social activities and obligations. Regarding the satisfaction with the sexual life, the results confirmed the assumption hypothesized by the investigator that the sexual dysfunction is more prevalent among the diabetics than among the non-diabetics. Many literature studies revealed that erectile dysfunction is a well-established complication of diabetes among men and the reported prevalence ranges from 35 to 70% (Veves et al., 1995; Fedele et al., 2000). Newman and Bertelson's 1986 study was methodologically very good and revealed that 47% of participating women reported sexual dysfunction. In order of importance, these women reported

decreased sexual arousal (lubrication) (32%), decreased sexual desire (21%), pain disorders (dyspareunia) (21%), and problems with orgasm (15%). Eighty-nine percent of these women reported that their problems occurred after their diagnosis of diabetes.

Subsection (9.2.17) showed that the majority of both groups were dissatisfied with the living conditions and the transport in the camps. These affect mainly the ability of the diabetic and chronically ill patients to manage their disease.

Figure (44) showed that about 82% of the diabetic refugees had negative feelings such as blue mood, despair, anxiety, depression quite often, very often, and always in comparison with only 27% of non-diabetics. This indicates that many diabetic refugees suffer from depressive and psychological symptoms, which have a great impact on the individual's functional ability, and quality of life, which in turn impairs adherence to medical treatment and glycemic control, and increases the risk of more and more diabetes complications. In a study conducted by Thomas et al. (2003) to determine whether type 2 diabetes contributes to the presence of depressive and anxiety disorder diagnoses in low-income adults, the results indicated that, after controlling for sex and education, a high prevalence rate of depressive and/or anxiety disorders was found in the total sample (29%) and in all three illness groups: type 2 diabetes (36%), other chronic illnesses (24%), and no chronic illness (31%). These findings confirm that the diagnosis of type 2 diabetes is associated with increased depressive and/or anxiety disorder among the diabetics and support prior research that diabetes may serve as an indicator of depression and anxiety in low-income adults treated in primary care clinics.

### **10.7 Effect of DM on the quality of life domains of the diabetic refugees by comparison of means and analysis of variance (ANOVA)**

As shown in table (40), big differences were found among the means of QOL domains of the diabetic refugees and the non-diabetic refugees. These results were also confirmed by the analysis of variance among the means of QOL domains for both groups. As shown in F-test table (41), diabetes mellitus had significant negative impacts on the four QOL domains as well as on the global value of the diabetic refugees. The strongest effect of DM was on the physical domain (F 345.991); this is because patients with diabetes are two to three times more likely to report

physical disability than their non-diabetic counterparts and diabetes as a chronic disease significantly limits daily activity in 60% of diabetic people >65 years of age compared with only 33.5% of those without diabetes (Adams, 1993). While the weakest effect was found to be on the environmental domain (F 51.59); this is because both groups live in the same camps and suffer from the same environmental irritants but the diabetic patients perceived their environment with more fears and worries because of their unknown future. It is concluded from this study that the refugees with diabetes have a worse QOL than the refugees with no chronic illness, thus, rejecting the null hypothesis which indicates no effect. These findings are in a full agreement with most of the previous studies of the diabetic patients and the different aspects of QOL. For example, a study (Goldney, 2004) aimed to assess the prevalence of diabetes and depression and their associations with quality of life using a representative population sample, revealed that, the prevalence of depression in the diabetic population was 24% compared with 17% in the non-diabetic population. Enzlin and associates (2003) revealed important evidence that women with diabetes are at increased risk for sexual problems. This evidence suggested that women with diabetes not only are prone to experience a decrease in sexual desire and more dyspareunia during sexual intercourse, but also are more likely to experience a decrease in sexual arousal involving slow or inadequate vaginal lubrication. Given these findings, this study confirms the hypothesis that, just as diabetic men are at higher risk for erectile dysfunction, so too are diabetic women at higher risk for sexual dysfunction in which the arousal phase is predominantly affected. Regardless of the pathophysiological defect causing hyperglycemia, there is a growing appreciation of the acceleration in risk for coronary heart disease (CHD) in women with any form of diabetes. The Framingham study first reported in 1979 that men and women with diabetes had a similar risk for CHD. This represented a doubling of overall risk compared to men without diabetes and a fivefold increase for women. Since this report, the increase in CHD risk in women with diabetes has been confirmed in other epidemiological studies (Howard et al., 1998; Koerbel, 2003).

Diabetes negatively affects not only the QOL of the adults but the children as well. A study (Castro et al., 2000) using the Child Behavior Checklist to determine whether having diabetes as a child affects psychological adjustment found that both internalized and externalized behavior problems were increased in children with diabetes. Boys with diabetes became more aggressive than boys without diabetes. In other study (Riddle, 2004) to estimate effects of diabetes on life expectancy, the predicted increase of mortality rates after diagnosis of diabetes was impressive.

Children developing diabetes in 2000 at age 10 were predicted to live about 19 fewer years than they would have without diabetes. Assuming that diabetes reduces the quality as well as duration of life, the loss of quality-adjusted life years (QALYs) for such children was predicted to be 31 for boys and 33 for girls.

### **10.8 Effect of the level of education on the QOL domains of the case and 2<sup>nd</sup> control groups by comparison of means and analysis of variance (ANOVA)**

As it was presented in tables (14 & 39), the educational attainment of the participants ranged from illiteracy to higher educational level. The comparison of means and the F-test (tables 42 & 43) presented significant effects of the educational level of the participants on the QOL. The higher the level of education, the better effect on QOL means. This reflects the importance of the education for the diabetic patients to be able to correctly manage their disease. Many illiterate diabetics complaint of lack of knowledge about the diet, exercise, insulin, the symptoms of the hyperglycemia and hypoglycemia and so on. The educated patients demonstrated more ability than the non-educated to read and understand the medication instruction, pamphlets, leaflets and the bulletins about the disease. They were also more capable to behave correctly in the emergency situations. Many of the illiterate or low-educated patients had false perceptions about diabetes. They turned too frequently not to the professional doctors or clinics but to the traditional healers who ordered for them ineffective and harmful traditional prescriptions. All of that led to worsening of their disease conditions and diminished the overall QOL.

### **10.9 Effect of employment status and income status on the QOL domains of the case and 2<sup>nd</sup> control groups by comparison of means.**

Based on the demographic and economical data of the participants (table 44), about 66% of the non-diabetic refugees were employed, however, most of them work in temporary jobs and gain approximately. By comparing the means of QOL domains among the employed and unemployed subjects, we found that the scores of the four domains of the employed were higher than the scores of the unemployed. Regarding the income status, there was a positive proportion between the QOL and the income status. In other words, the higher the monthly income, the better the QOL scores (table 45). We can conclude from this part that a good economic situation is a crucial factor for improving the QOL of the refugees especially those who suffer from a chronic disease like diabetes, which continuously needs more money to get an acceptable level of care.

### **10.10 The effect of the refuge life and DM on the QOL determinants of the diabetic refugees by odds ratios.**

The odds ratios tables (38) and (46) confirmed the previous results by the cross tabulations in the subsections (8.3) & (9.2) and the ANOVA tests in the subsections (8.4.1) and (9.3) that the diabetic refugees are more likely to have lower QOL scores than the diabetic non-refugees because of the effect of the refuge life and than the non-diabetic refugees because of the effect of DM. The probability of the diabetic refugees of suffering from pain is 8 times more than the non-refugees (OR, 8.4; 95% CI, 5.27 – 13.20) and 21 times more than the non-diabetic refugees (OR, 21.2; 95% CI, 11.96 – 37.38). The risk probability of having poorer health of the diabetic refugees is 5 times more than the diabetic non-refugees (OR, 5.8; 95% CI, 3.76 – 8.98) and 27 times than the non-diabetic refugees (OR, 27.7; 95% CI, 15.54 – 49.47). This trend is applied also for all of the other QOL items of the WHOQOL questionnaire, e.g., they reported more sleep disturbances than the other two groups (OR, 9.9), having more negative feelings (OR, 8.7; OR, 12.7), were more dissatisfied with the sexual life (OR, 2.3, OR, 13.2) etc. This indicated that living in a refugee camps in Gaza strip and having diabetes increase the risks to have poorer QOL in all domains about 4 to 27 times than the diabetic non-refugees and the non-diabetic refugees. We can conclude that the refuge life and DM have enormous negative effects on the different quality of life domains.

### **10.11 Strengths and limitations of the study**

This study has several strengths and some limitations. The investigator has chosen a cross-sectional paired matched case-control design for this study, which is recommended by several researchers (Smith, 2004). The case-control design has become a common and important method used to study many epidemiological and clinical questions (Fletcher et al., 1996). This design has several advantages: first, the investigator can identify cases unconstrained by the natural frequency of the disease and yet can still make a comparison. Case-control studies are relatively inexpensive and easy to assemble large number of cases from hospitals or community health centers, and similar groups without the disease and compare the past experience under study. A real advantage of the case-control study is its ability to address important questions rapidly and efficiently as long as their results are valid and reliable.

The strategy of choosing more than one control group is an efficient method to guard against the difficulties attending the selection of truly comparable control groups and against a systematic error in the odds ratio, which may arise from the selection bias.

Dividing the population into stratum and then selecting the sample size in proportion to the size of the stratum is an important strength of this study. According to Pilot et al. (1995) a probability proportionate stratified sampling can guarantee a great degree of representativeness of different segments of the population. Moreover, homogeneity and blocking were used to control extraneous variables.

One of the most important strengths of this study is the combination between the quantitative and the qualitative designs. Although the quantitative approach helped to include a large sample size of the refugees and non-refugees, the qualitative approach, however, helped to provide rich and meaningful information about the refugees' experiences with diabetes and their QOL. It provided a detailed and extensive understanding of how the diabetic refugees perceive their conditions, how they and their families were affected by the disease, and how they feel about their refugee status in the camps and their health conditions in general.

This study focused on the socio-cultural aspects of the life of the refugees. It helps to understand how the Palestinian refugees manage their diabetes mellitus and their daily activities under the difficult conditions of the refuge life in the camps and how they evaluate the health services provided for them which could help future researches to improve the quality of these health services and then the quality of the refugees' lives.

Although this study has several strengths, it has some limitations. The study has limited generalizability to other health problems and settings. For example, this study could not be generalized for patients with other diseases like hypertension or heart diseases. Also, the results of this study could be partially generalized to the other diabetic Palestinian refugees who live outside Palestine (e.g., Jordan, Syria, Lebanon, etc.), because the political and life conditions of every diabetic Palestinian refugee community are partially different.

Selection bias may be another limitation of this study. However, many procedures have been adopted to minimize it such as matching, homogeneity, and blocking.



One of the most difficult points that faced the investigator and his team was the time interruptions during the data collection period. As a result of the military escalation and the occupation procedures on the ground (e.g., closure of the roads, curfews and military incursion), the interviewers had to wait for long time to reach the subjects in their clinics or at homes, which affected the consistency of the data collection. Assessing the QOL and conducting the interviews have to be done within a limited period of time among all the subjects; this is why the time factor was a major concern in this study.

**At the end of this chapter,** we can conclude that the objectives of the study have been met and the proposed hypotheses have been tested and answered as the following:

### **1. Null hypothesis**

There is no difference between QOL of the diabetic refugees in the refugee camps and the diabetic non-refugees in the cities.

The first null hypothesis was rejected and the alternative hypothesis was accepted indicating that the diabetic non-refugees showed greater increase in QOL scores than the diabetic refugees who live in the refugee camps in Gaza strip

### **2. Null hypothesis**

There is no difference between QOL of the diabetic refugees and the non-diabetic refugees who reside in the refugee camps in Gaza strip.

The second null hypothesis was also rejected and the alternative hypothesis was accepted indicating that non-diabetic refugees showed greater increase in QOL scores than the diabetic refugees in the refugee camps.

### **3. Null hypothesis**

There is no relationship between the age, sex, income, level of education, duration of diabetes, and type of diabetes and the QOL of the diabetic refugees.

### **Alternative hypotheses**

- Older diabetic refugees show greater decrease in QOL scores than younger diabetic refugees.
- Male diabetic refugees show higher QOL scores than the females.

- High-income and well-educated refugees show higher QOL scores than those who are low-income and non-educated.
- Type 2 diabetics show better QOL than Type 1 diabetics.
- Patients with long duration of diabetes have lower QOL scores than those with short duration diabetes.

Regarding the third null hypothesis, the results led to *partially* rejecting the null hypothesis and showing that: older diabetic refugees showed greater decrease in QOL scores than younger diabetic refugees; male diabetic refugees showed higher QOL scores than the females; high-income and well-educated refugees showed higher QOL scores than those who are low-income and non-educated; and patients with long duration of diabetes have lower QOL scores than those with short duration diabetes. But for Type 1 and Type 2 diabetics: *there was no differences between the QOL of Type 1 and Type 2 diabetics.*

#### **4. Null hypothesis**

There is no difference between QOL scores of the diabetic refugees who developed complications and those without complications.

The fourth and the last null hypothesis was rejected and the alternative hypothesis was accepted indicating that the diabetic refugees who developed complications had lower QOL scores than those who did not.

Regarding the third research objective “To compare between the quality of health services provided by UNRWA and the MOH for the diabetic patients in Gaza strip”, the results of the study indicated that the majority of the diabetic refugees were not satisfied with the health care provided by the UNRWA centers in the refugee camps in comparison with the health care provided by the MOH. The major sources of their dissatisfaction were the absence of a comprehensive physical examination, ineffective therapeutic communication among the health staff and the clients, the crowdedness of the clinics and the disproportionate number of health personnel to the number of clients.

## **Chapter 11**

### **Recommendations and implications of the study**

Diabetes mellitus, especially type 2 diabetes is a serious disease and a cause for growing public health concern in most countries including Palestine. It is now a leading cause of death, disability and a high health care cost, which should urge all health authorities to be ready for this challenge. Zimmet (2003) in his article stated that: controlling the type 2 diabetes epidemic will require changes to the structure of health care delivery. Well-resourced interventions will be required, with effective coordination between all levels of government, health care agencies, multidisciplinary health care teams, professional organizations, and patient advocacy groups. Above all, intervention is needed today.

This research provides a clear picture of the diabetes mellitus in Palestine especially among the refugees and suggests a comprehensive management plan to minimize the daunting outcomes of diabetes and improve the quality of life of the diabetics. Accordingly, five general recommendations must be taken into consideration:

1. To promote evidence-based diagnosis and management guideline of diabetes mellitus suitable for local situation which will help improving patient's clinical outcomes and his quality of life.
2. To help primary and secondary health care providers in the early detection of diabetes, proper clinical assessment and delivery of appropriate individualized interventions.
3. To help in reducing the outcome of chronic complications of diabetes.
4. Assist primary and secondary health care providers in the proper management of gestational diabetes.
5. To allow flexibility so that local practice and individual situations can be accommodated.

These five recommendations can be implemented through the following measures:

#### **11.1 Restructuring the health care system**

The provision and organization of diabetic care is complex and multilayered and are influenced by local, national and international bodies and integrated approach to diabetic care must be

emphasized. This means that provision of appropriate health care for diabetics should take into consideration all the major health components of the health care system, including:

- Assessment of local needs and measures,
- Consensus of standards of care,
- Mechanisms for translating recent advances in research into community practice,
- Appropriate education and utilization of off all categories of health care professionals, and
- Continuing evaluation of the quality and effectiveness of patient management.

Concreted efforts should be made to orient comprehensive health care systems towards the following goals:

- Identification of high-risk subjects at an early stage and, where possible, provision of health education aimed at primary prevention;
- Early diagnosis of diabetes and institution of management to reduce morbidity and mortality;
- Prevention and early recognition of acute complications and the institution of effective treatment;
- Education of the patient and the patient's family, in methods of self-care within home environment;
- Provision of equal opportunities for fulfillment of educational, physical, psychological, and employment potentials; and
- Identification and rehabilitation of diabetics who are partially or totally disabled.

Planning is the keystone of a comprehensive strategic health system that provides appropriate treatment for diabetics at the primary, secondary, and tertiary level.

Primary health care must be easily accessible to patients and their families, and compatible with their culture and beliefs. It is also important that primary health care be linked and coordinated with other levels of care such as secondary and tertiary levels. Any system of primary health care that attempts to cover a large population at relatively low cost must depend upon allied health professionals and adequate support from appropriate levels of secondary and tertiary care. In most of the developed countries, the primary health care system is based upon a trained team of physicians, community nurses, and dieticians.

## **11.2 Policy and management**

It is concluded from this study that the quality of health care provided for the diabetic refugees is poor which led to the deterioration of the quality of life. Therefore, one way to improve the QOL of the diabetics in Gaza strip and West Bank is to improve the quality of care available to those patients.

The first step to achieve this major goal is the assessment, because “*assessment of the quality of care would lead to improvements*” (Fleming et al., 2001). In order to assess more completely the level of diabetes care delivered in Palestine, we need standardized uniform performance measures that can assess quality of care accurately and reliably. It was recognized that a national consensus on measures could enhance this process and provide a method for assessing care within and across health care settings while providing a meaningful mechanism for quality improvement. In this regard, it is recommended in Palestine to develop and implement a comprehensive set of national measures for evaluation and quality improvement of diabetic care (Diabetes Quality Improvement Project (DQIP)). The goals of developing the DQIP are: DQIP provide readily available methods to evaluate interventions to improve diabetes care; DQIP serve as a template for performance measurement for organizations seeking to improve care for diseases or conditions other than diabetes. For diabetes morbidity specifically, the ultimate effect of DQIP will become apparent as data are publicly reported and used for quality improvement. Finally, use of the DQIP measure set will no doubt play a critical role in translating today’s clinical interventions into practice that will improve quality of life and clinical outcomes for diabetic patients and help us to gain an edge on the diabetes epidemic.

The second step to improve the diabetes management and the quality of life of the Palestinian diabetics is to create a National Diabetes Care Model, a 'top-down' approach to incorporate diabetes care and education in the Palestinian health care system. The approach is by way of trained diabetes teams consisting of physicians, dieticians and nurse educators at national levels (in Gaza strip and West Bank) who in turn train teams consisting of physicians, dieticians or diet therapy nurses, nurse educators and pharmacists at regional and district/sub-regional levels to offer care and education to patients and the community. In three years selected participants from all regional and sub-regional/district health facilities have to meet to evaluate if the program objectives have been met. The success of this project will give an impetus to the collaborators to extend the program to other health care levels such as private sectors. A similar program has been

developed and implemented in Ghana, a developing country. According to Amoah et al. (2000), after three years of launching this program all regional and about 63% of sub-regional/district health facilities had trained diabetes health care teams, run diabetes services and had diabetes registers at these institutions and the program was extended to the primary health care level.

### **11.3 Implications for practice**

It is important that the diabetic refugees be recognized and treated as individuals, with consideration of their family situation. Their perception of the disease influences how they manage diabetes, which in turn affects their quality of life. Usually the patients have different styles in dealing with the disease and health care providers need to understand how they define and manage their condition. Furthermore, they need to help the diabetic refugees establish appropriate and acceptable management behaviors according to their circumstances. Therefore, health care personnel need to be aware of the important factors and aspects of the refugees' management of diabetes in order to meet their health needs as effectively as possible. Therefore, the management plan should consider the following:

- A complete, organized medical record system is essential to provide a base for ongoing care of people with diabetes.
- The management plan should be individualized, the management plan should be formulated in collaboration with the patient, and the plan should emphasize the involvement of the patient in problem solving as much as possible. A variety of strategies and techniques should be employed to provide adequate education and development of problem-solving skills in the various aspects of diabetes management.
- In formulating this management plan, consideration should be given to the patient's age, school or work schedule and conditions, physical activity, eating patterns, social situation and personality, cultural factors, and presence of complications of diabetes or other medical conditions.
- Implementation of the management plan requires that each aspect is understood and that the goals and treatment plan are reasonable.
- Continuing care is essential in the management of every patient with diabetes. At each visit, the patient's progress in achieving treatment goals should be evaluated by the health care team, and problems that have occurred should be reviewed. If goals are not being met, the management plan needs to be revised and/or the goals need to be reassessed.

Health care providers need to provide enough time for diabetic patients to discuss their care, illness, treatment and the progress of their condition over time. Also, encouragement needs to be conveyed to the refugees who tried hard to comply with the strict and difficult regimen for diabetes care in spite of the scarce resources in the camps.

Acknowledging the refugees' efforts to adhere to the difficult regimen and providing positive feedback might further facilitate their important role in self-care and contribute to their overall health and well-being. Health care providers need to provide support to the diabetic refugees during the critical times of their illness. Some of them have fears and feelings of despair that increase during crises periods; therefore, they need sufficient support during these periods. Also, most of the diabetic refugees reported severe initial reactions to the diagnosis of diabetes, a finding that highlights the importance of support by the health care providers at the time of diagnosis.

Health care providers need to advise the parents of young diabetics about how to deal with and treat diabetes and reduce the negative feelings that the patients and their parents might have, especially at the time of diagnosis and later on. Parents and school personnel need to be involved and informed about the care of young school-age diabetics in a way that does not inhibit their ability to care for themselves and to continue their school work. They need to prevent overprotection of the young patients and allow them to live normally and maintain regular life activities.

Since acceptance by peer group is important at younger ages, the young diabetic patients should be recognized by the families, peers, teachers and classmates, and health care providers in order to minimize the feelings of being different from others and help them to live as normally as possible. To do this, the school health program should provide health education about dealing with chronic health conditions and the importance of supporting classmates who have any health problem.

#### **11.4 Implications for health education**

Education is an essential part of diabetes management. Education and training of patients and their families are the foundations of good diabetic therapy. Education of the general public is an

integral part of a prevention-oriented approach to diabetes mellitus. Accurate and comprehensible information must be provided for populations with a wide variety of educational levels. Five interlinked groups must be included in the education process: patients with diabetes, the patient's family, health care personnel, and the community and health policy planners. It is essential that these groups work together and interact with each other in order to achieve the desired outcomes of the education process.

Its purpose is to make persons with diabetes and their families as knowledgeable and self sufficient as possible. The short-term goal is to maximize diabetes control, and the long-term goal is to minimize the impact of chronic complications of diabetes and to improve quality of life.

We found in this study that many diabetic patients lack sufficient information about the disease and its processes and complications to manage the disease in the most effective way. Adequate information would facilitate management and health care providers should provide accurate, relevant and simple (according to the level of literacy) information about the disease and treatment. In turn this will decrease the patients' fears and worries about the disease and motivate them to carry out the appropriate care practices.

Health educators need to be aware of patients' feelings and thoughts regarding their care and respect them as they provide information and education. Some education groups could be planned at the clinic while diabetic patients are waiting for appointment. These sessions could use the peer group education approach, where discussing common problems and situations with other patients having the same or similar problem may decrease the stress and help them cope with their situation in a better way. Since most of the old diabetic refugees can not read or write, providing the traditional written pamphlets concerning basic knowledge of diabetes and how to manage would not be useful. Rather the pamphlets should emphasize pictorial way of teaching.

Trained community nurses and workers would be helpful in conducting home visits and education for the diabetic refugees in their own environment and based on the refugee and family's needs. Therefore, assessing determinants of individuals' perceived QOL should be of importance to policy makers and policy decisions should be based in part on the refugees' perception of their own lives.



In summary, the following points are important to be considered when planning education program for diabetics:

1. Basically diabetes education should include education on diabetes and its treatment as well as instruction on the prevention of complications of diabetes, such as hypoglycemia and foot problems.
2. Diabetes education should focus on compliance to treatment to help people cope with the disease and its various demands such as diet adjustment, injections, monitoring and social adjustment.
3. Education should be targeted at a level, which the individual patient can understand, using different methods as lecturing, instruction, demonstration and teaching by example.
4. Educators should be sympathetic and understanding when dealing with people with diabetes.

### **11.5 Implications for diabetes prevention and health promotion**

To stem the rising tide of diabetes, public health policies in Palestine need to move upstream toward prevention or at least a delay in the onset of type 2 diabetes. A number of recent studies (Satterfield et al., 2003) offer scientific evidence and new hope for curtailing the epidemic of type 2 diabetes with support for intensive lifestyle modification and modest weight loss as effective interventions among adults at high risk for developing type 2 diabetes.

Diabetes screening programs have to be initiated for the detection of pre-diabetes in the Palestinian community; the lengthy developmental period of diabetes, coupled with the potential to prevent or delay the onset of type 2 diabetes, offers an opportunity for multifaceted prevention efforts. The current evidence suggests that opportunistic screening to detect pre-diabetes (IFG or IGT) should be considered in individuals  $\geq 45$  years of age, particularly in those with a BMI  $\geq 25$  kg/m<sup>2</sup>. Screening should also be considered for people who are  $< 45$  years of age and who are overweight if they have another risk factor for diabetes (e.g., family history, hypertension, dyslipidemia).

The case for screening is strengthened by the fact that screening will not only detect cases of IFG or IGT, but also cases of undiagnosed diabetes. Thus, policies to identify individuals for whom it is appropriate to initiate a diabetes prevention strategy will also identify individuals who should receive treatment for diabetes. Furthermore, because individuals with IFG, IGT, or undiagnosed

diabetes are at high risk for cardiovascular disease, their identification should herald increased surveillance and treatment for hypertension, dyslipidemia, and heart diseases.

Distinct preventive medicine strategies must be established by the MOH and UNRWA as follows: 1) the "high-risk approach," which identifies and focuses exclusively on individuals at highest risk for developing diseases; and 2) the "population or public health approach," which attempts to reduce risk factors for or causes of diseases within the Palestinian community, which are generally defined in terms of localities but can also represent groups who share a common cause or interest. Rose (Rose, 1985) identified advantages and disadvantages for both approaches. For example, the high-risk approach is generally cost-effective with a high likelihood of benefit for motivated individuals. The population approach, often called the community-based approach, offers a smaller benefit to individuals but more potential for benefiting the larger population. Whereas the high-risk approach is palliative, the community-based approach aims to address the underlying causes of ill health; the latter is typically predicated on respect for community strengths, including cultural practices and wisdom, with meaningful participation of the community from the beginning. Both high-risk and community-based approaches are likely to be required for the challenging goals of preventing or delaying type 2 diabetes and tend to be valued by local communities because they can ensure the cultural relevance of interventions.

Palestinian Governmental and Non-Governmental agencies, voluntary organizations, and others have to play more coordinated roles to reduce the burden of diabetes by translating research findings into practice at multiple levels (primary, secondary, and tertiary), including providing support and assistance to develop comprehensive and sustainable programs to prevent and treat diabetes among the different Palestinian Provinces in Gaza Strip and West Bank.

A concerted effort to increase application of public health and clinical interventions of known efficacy to reduce prevalence of poor diet, and insufficient physical activity—the major risk factors for diabetes—and to increase utilization of screening tests for their early detection could substantially reduce the human and economic cost of diabetes and other chronic diseases.

The Palestinian Legislative Council can also contribute in this campaign by issuing legislative action that results in more funding for and access to primary prevention programs and research,

and reconsideration of the concept of the periodic medical checkup as an effective platform for prevention, early detection, and treatment of diabetes.

### **11.6 Implications for future research**

Improvement of the health status of the diabetics depends on both effective health care and related research. Absence of scientific research on diabetic refugees reflects the lack of international awareness of the size and the extent of this problem. Previous research about the QOL of the Palestinian refugees with diabetes or about the management of chronic health conditions among refugees was not found. This study is the first to describe how the diabetic refugees in Gaza strip perceive their quality of life under the difficult conditions of the refugee life. Therefore, further research should continue the exploration of the experience of the refugees having chronic conditions, including diabetes. Such studies should be designed to develop a solid understanding of refugees and their health in order to develop an understanding of the determinants of health behaviors from a refugee perspective.

Other health conditions need to be investigated and compared to diabetes, especially cancer and heart diseases. It is recommended that future studies compare the experiences and quality of life among the refugee men and women separately in and outside the camp settings. Such gender-directed research is very important to understand the main differences between both sexes in order to reach a more individualized health care plan for individuals and families with diabetes.

Because of objective and logistic limitations, this study was conducted for the diabetic refugees in Gaza strip. Therefore, it is recommended in the future to expand this research in the other settings where the Palestinian refugees reside, such as West Bank, Jordan, Lebanon and Syria, in order to gain a collective perception of the refugee experience with diabetes.

Longitudinal studies might help in understating how the refugees with diabetes cope and change their understandings, feelings, and management of diabetes over time. Special attention to studies of young people with diabetes in Palestine would help teenagers manage the development process with a chronic life life-long condition that would not have to restrict their life activities. Studies of refugees with diabetes at different stages of their life (age, marital status, education) are needed. In addition, cross-cultural studies might help to understand the influence of culture and religion on the definition and management of health conditions.

Since most studies on refugee population (Muecke, 1992) focused on the effects of the trauma suffered by the torture victims on their psychological health, more studies are needed in the areas of chronic conditions and refugees' ways and behaviors of managing their conditions. Also, follow-up studies of refugees are needed once they settle down in one country to evaluate their adaptation and coping with environment, and in turn, assess the effects of their experience on how they perceive and manage their health.

Methodologically, it is important to use multidimensional assessments of quality of life, and to include both generic and disease-specific measures. Also, quality of life measures should be used to guide and evaluate treatment interventions.

There is a major need for: (i) community-based researches; (ii) study of the most cost-effective ways of delivering diabetes health care, including preventive services; and (iii) evaluation of the methods used in programs of diabetes education.

Health system research is needed to develop a comprehensive diabetes health care program that is linked with community control programs for other non-communicable diseases and that can be integrated into national health systems, particularly at the Palestinian national health level. Such a program should be multidisciplinary, with emphasis on social and behavioral aspects of diabetes care, and should aim at improving the delivery of health care services, use comparative methods of investigation, help promote the application of existing and advancing biomedical knowledge, and provide a sound foundation for health planning and policy formulation.

## **Chapter 12**

### **Conclusion**

Although diabetes cannot be cured, it can be controlled. Its effect on the QOL can be minimized and careful management can delay or prevent its long-term complications. It is important to understand that diabetes management is more of a psychological problem than a biological one (Shillitoe, 1988) particularly because the behaviors, attitudes and circumstances of the patient are the key determinants for achieving metabolic control, which in turn, improves the quality of their lives.

Most of the diabetic refugees in the camps reported poor and very poor QOL compared with the other two control groups. The Palestinian diabetic refugees, in addition to disease process that they are going through, are deprived of certain social and economic benefits. This indicated that the QOL of the Palestinian refugees in general and the diabetics in particular continues to spiral downward in response to ongoing hardships, suppression and the lack of health services.

The burden and difficulty felt by the diabetic refugees in adhering to therapeutic regime, as well as the conflict between having to carry out social roles and the necessity to sustain self-management behavior have been revealed to have a great influence on the diabetic refugees' quality of life

This study approved that the diabetic complications (blindness, dialysis, symptomatic neuropathy, foot ulcers, amputation, stroke, and congestive heart failure) were associated with more substantial reductions not only in the physical abilities of the refugees but also in their psychological wellness.

The existing diabetes care services in Gaza strip are less than the needs of the patients. Upgrading professionals' skills especially for staff running the NCD clinics through in-service training by specialist in different aspects of diabetes, and availability of needed medications in due time are very essential to improve the control and prevention measures.

Combining quantitative and qualitative measures provided an important assessment of the QOL of the diabetic refugees in Gaza strip. This study provided rich and meaningful information about the refugees' experience with diabetes. It provided a detailed and extensive understanding of how

the refugee status affected their QOL, how they and their families affected by the disease, and how diabetes with scarce health resources influenced their daily activities. Since the effectiveness of diabetes management is to a large extent dependent on the patient, it is important to help diabetic patients minimize psychological distress and unnecessary impairment of QOL.

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## APPENDICES

- Appendix A**      Consent Form
- Appendix B**      Demographic information sheet
- Appendix C**      World Health Organization Quality of Life Questionnaire- short version (WHOQOL-BREF)
- Appendix D**      Post Hoc comparisons among the age and quality of life domains of the diabetic refugees and non-refugees by using Scheffe technique
- Appendix E**      Multiple comparisons of the significant differences between the duration of diabetes and the QOL domains among the diabetic refugees and non-refugees using Scheffe test.
- Appendix F**      Post Hoc Multiple comparisons (Scheffe test) among the significant differences between the complications of diabetes among the case and control.
- Appendix G**      Interview transcription

## Appendix A

### Consent Form

#### Dear Participant,

I am a Doctorate student in the faculty of public health at the University of Bielefeld -Germany. I am conducting a research study about the quality of life of the diabetic Palestinian refugees who live in the refugee camps in Gaza strip.

You are invited to participate in this study. The following information is provided in order to help you to make an informed decision whether or not to participate. If you have any question, please do not hesitate to ask.

**The general purpose of this study is to assess and evaluate the quality of life of the diabetic Palestinian refugees who live in the refugee camps in Gaza strip. This study sought an understanding of how the Palestinian refugees manage their diabetes mellitus and their daily activities under the difficult conditions of the refuge life in the camps; how they evaluate the health services provided for them in the camps and how these impact on the quality of their lives.**

This aims of this study are, first, to provide a general understanding of the experience of having and managing diabetes from the views of refugees in their camps and how this impacts on their quality of their lives; second, to provide valid and reliable information that help in improving the quality of life not only for the diabetic refugees but also for all diabetic non-refugees and non-diabetic refugees in Gaza strip. Third, health managers, administrators and policy-makers can also use the results of this study to plan for effective public health programs for diabetics to improve their abilities to control their disease and prevent its complications.

Your participation in this study is voluntary. You are free to decide not to participate in this study without adversely affecting the health services that you or any member of your family may receive from UNRWA or the Ministry of Health. Please do not include your name in your response. All responses will be confidential and will be considered only in combination with those from other participants. The information obtained will be used only for scientific study purposes and may published in scientific journals or presented at scientific meetings.

Thank you very much for your completing the questionnaire and I appreciate the time you will take to complete this study.

Sincerely,

The resaercher

Ashraf Eljedi

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Participant's Signature.

## Appendix B

### Demographic Info Sheet

#### ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

#### I. Demographic data

1. What is your **gender**?  Male  Female
2. What is your **date of birth**? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Day / Month / Year
3. What is the highest **education** you received?  None at all  Primary school  
 Secondary school  Tertiary school  
 Higher education
4. What is your **marital status**?  Single  Married  
 Divorced  Widowed
5. Do you **live** in a:  Refugee camp  Village  City

#### II. Socio-economic status

6. Is your **house**?  Own  UNRWA  rent  
 Others, \_\_\_\_\_
7. **Occupation**  employed  unemployed
8. **Income** status:  \_\_\_\_\_
9. How many persons are financially **dependent on you**?  \_\_\_\_\_

#### III. Health Profile

10. When did you first come to know that you have **Diabetes**?  \_\_\_\_\_
11. What is the **type** of your diabetes?  Type I  Type II  
 Others, \_\_\_\_\_
12. What type of **medication** are you taking for diabetes?  Pills  Insulin  
 Both  nothing
13. Do you suffer from any **complications** of the diabetes?  Retinopathy  Nephropathy  
 Neuropathy  Diabetic foot
14. Do you suffer from other **chronic disease**?  Heart diseases  Stroke  
 Cancer  Rheumatic

Appendix c

# WHOQOL-BREF



**PROGRAMME ON MENTAL HEALTH  
WORLD HEALTH ORGANIZATION  
GENEVA**

*For office use only*

	Equations for computing domain scores	Raw score	Transformed scores	
<b>Domain 1</b>	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ $\square + \square + \square + \square + \square + \square + \square$	=	<b>4-20</b>	<b>0-100</b>
<b>Domain 2</b>	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ $\square + \square + \square + \square + \square + \square$	=		
<b>Domain 3</b>	$Q20 + Q21 + Q22$ $\square + \square + \square$	=		
<b>Domain 4</b>	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ $\square + \square + \square + \square + \square + \square + \square + \square$	=		

## Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the six months.**

For example, thinking about the six months, a question might ask:

	<b>Not at all</b>	<b>Not much</b>	<b>Moderately</b>	<b>A great deal</b>	<b>Completely</b>
<b>Do you get the kind of support from others that you need?</b>	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

	<b>Not at all</b>	<b>Not much</b>	<b>Moderately</b>	<b>A great deal</b>	<b>Completely</b>
<b>Do you get the kind of support from others that you need?</b>	1	2	3	<u>4</u>	5

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
<b>1(G1)</b>	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<b>2(G4)</b>	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last six months.

		Not at all	A little	A moderate amount	Very much	An extreme amount
<b>3(F1.4)</b>	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
<b>4(F11.3)</b>	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
<b>5(F4.1)</b>	How much do you enjoy life?	1	2	3	4	5
<b>6(F24.2)</b>	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
<b>7(F5.3)</b>	How well are you able to concentrate?	1	2	3	4	5
<b>8(F16.1)</b>	How safe do you feel in your daily life?	1	2	3	4	5
<b>9(F22.1)</b>	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last six months.

		Not at all	A little	Moderately	Mostly	Completely
<b>10(F2.1)</b>	Do you have enough energy for everyday life?	1	2	3	4	5
<b>11(F7.1)</b>	Are you able to accept your bodily appearance?	1	2	3	4	5
<b>12(F18.1)</b>	Have you enough money to meet your needs?	1	2	3	4	5



<b>13(F20.1)</b>	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
<b>14(F21.1)</b>	To what extent do you have the opportunity for leisure activities	1	2	3	4	5

		<b>Very poor</b>	<b>Poor</b>	<b>Neither poor nor good</b>	<b>Good</b>	<b>Very good</b>
<b>15 (F9.1)</b>	How well are you able to get around?	1	2	3	4	5

**The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last six months.**

		<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither satisfied nor dissatisfied</b>	<b>Satisfied</b>	<b>Very satisfied</b>
<b>16 (F3.3)</b>	How satisfied are you with your sleep?	1	2	3	4	5
<b>17(F10.3)</b>	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
<b>18(F12.4)</b>	How satisfied are you with your capacity for work?	1	2	3	4	5
<b>19 (F6.3)</b>	How satisfied are you with yourself?	1	2	3	4	5
<b>20(F13.3)</b>	How satisfied are you with your personal relationships?	1	2	3	4	5
<b>21(F15.3)</b>	How satisfied are you with your sex life?	1	2	3	4	5
<b>22(F14.4)</b>	How satisfied are you with the support you get from your friends?	1	2	3	4	5
<b>23(F17.3)</b>	How satisfied are you with the conditions of your living place?	1	2	3	4	5
<b>24(F19.3)</b>	How satisfied are you with your access to health services?	1	2	3	4	5
<b>25(F23.3)</b>	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last six months.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Do you have any comments about the assessment?

.....  
.....

**THANK YOU FOR YOUR HELP**

## Appendix D

**Post Hoc comparisons among the age and quality of life domains of the diabetic refugees and non-refugees by using Scheffe technique**

QOL domains	Age	Age in years	Mean Difference	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Physical domain	Less than 30	30-39	-2,4881	6,88540	,998	-23,7990	18,8228
		40-49	-,8248	6,12842	1,00	-19,7928	18,1431
		50-60	8,2424	5,97114	,753	-10,2387	26,7236
		> 60	20,1956(*)	6,12842	,030	1,2276	39,1635
	30-39 years	< 30	2,4881	6,88540	,998	-18,8228	23,7990
		40-49	1,6633	4,96265	,998	-13,6965	17,0231
		50-60	10,7305	4,76706	,283	-4,0239	25,4849
		> 60	22,6837(*)	4,96265	,000	7,3239	38,0435
	40-49 years	< 30	,8248	6,12842	1,00	-18,1431	19,7928
		30-39	-1,6633	4,96265	,998	-17,0231	13,6965
		50-60	9,0673	3,58799	,174	-2,0379	20,1724
		> 60	21,0204(*)	3,84405	,000	9,1228	32,9181
	50-60 years	< 30	-8,2424	5,97114	,753	-26,7236	10,2387
		30-39	-10,7305	4,76706	,283	-25,4849	4,0239
		40-49	-9,0673	3,58799	,174	-20,1724	2,0379
		> 60	11,9532(*)	3,58799	,027	,8480	23,0583
	More than 60	< 30	-20,1956(*)	6,12842	,030	-39,1635	-1,2276
		30-39	-22,6837(*)	4,96265	,000	-38,0435	-7,3239
		40-49	-21,0204(*)	3,84405	,000	-32,9181	-9,1228
		50-60	-11,9532(*)	3,58799	,027	-23,0583	-,8480
Psychological domain	Less than 30	30-39	-6,4762	6,80155	,923	-27,5275	14,5752
		40-49	-4,2823	6,05379	,973	-23,0193	14,4547
		50-60	1,2500	5,89842	1,00	-17,0061	19,5061
		> 60	10,0238	6,05379	,602	-8,7132	28,7608
	30-39 years	< 30	6,4762	6,80155	,923	-14,5752	27,5275
		40-49	2,1939	4,90222	,995	-12,9789	17,3666
		50-60	7,7262	4,70901	,611	-6,8486	22,3009
		> 60	16,5000(*)	4,90222	,024	1,3272	31,6728
	40-49 years	< 30	4,2823	6,05379	,973	-14,4547	23,0193
		30-39	-2,1939	4,90222	,995	-17,3666	12,9789

		<b>50-60</b>	5,5323	3,54430	,656	-5,4376	16,5022
		<b>&gt; 60</b>	14,3061(*)	3,79724	,007	2,5533	26,0589
	<b>50-60 years</b>	<b>&lt; 30</b>	-1,2500	5,89842	1,00	-19,5061	17,0061
		<b>30-39</b>	-7,7262	4,70901	,611	-22,3009	6,8486
		<b>40-49</b>	-5,5323	3,54430	,656	-16,5022	5,4376
		<b>&gt; 60</b>	8,7738	3,54430	,192	-2,1961	19,7437
		<b>More than 60</b>	<b>&lt; 30</b>	-10,0238	6,05379	,602	-28,7608
	<b>30-39</b>		-16,5000(*)	4,90222	,024	-31,6728	-1,3272
	<b>40-49</b>		-14,3061(*)	3,79724	,007	-26,0589	-2,5533
	<b>50-60</b>		-8,7738	3,54430	,192	-19,7437	2,1961
<b>Social domain</b>	<b>Less than 30</b>	<b>30-39</b>	-3,3036	5,19385	,982	-19,3790	12,7718
		<b>40-49</b>	-1,0655	4,62284	1,00	-15,3736	13,2426
		<b>50-60</b>	1,5720	4,50420	,998	-12,3689	15,5128
		<b>&gt; 60</b>	10,9753	4,62284	,230	-3,3327	25,2834
	<b>30-39 years</b>	<b>&lt; 30</b>	3,3036	5,19385	,982	-12,7718	19,3790
		<b>40-49</b>	2,2381	3,74347	,986	-9,3482	13,8244
		<b>50-60</b>	4,8755	3,59593	,765	-6,2541	16,0052
		<b>&gt; 60</b>	14,2789(*)	3,74347	,006	2,6926	25,8653
	<b>40-49 years</b>	<b>&lt; 30</b>	1,0655	4,62284	1,00	-13,2426	15,3736
		<b>30-39</b>	-2,2381	3,74347	,986	-13,8244	9,3482
		<b>50-60</b>	2,6374	2,70652	,917	-5,7395	11,0144
		<b>&gt; 60</b>	12,0408(*)	2,89968	,002	3,0661	21,0156
	<b>50-60 years</b>	<b>&lt; 30</b>	-1,5720	4,50420	,998	-15,5128	12,3689
		<b>30-39</b>	-4,8755	3,59593	,765	-16,0052	6,2541
		<b>40-49</b>	-2,6374	2,70652	,917	-11,0144	5,7395
		<b>&gt; 60</b>	9,4034(*)	2,70652	,018	1,0265	17,7803
	<b>More than 60</b>	<b>&lt; 30</b>	-10,9753	4,62284	,230	-25,2834	3,3327
		<b>30-39</b>	-14,2789(*)	3,74347	,006	-25,8653	-2,6926
		<b>40-49</b>	-12,0408(*)	2,89968	,002	-21,0156	-3,0661
		<b>50-60</b>	-9,4034(*)	2,70652	,018	-17,7803	-1,0265
<b>Environment domain</b>	<b>Less than 30</b>	<b>30-39</b>	-5,6369	6,69441	,950	-26,3566	15,0828
		<b>40-49</b>	-2,0553	5,95843	,998	-20,4971	16,3865
		<b>50-60</b>	-,1477	5,80551	1,00	-18,1162	17,8208
		<b>&gt; 60</b>	4,9549	5,95843	,952	-13,4869	23,3967
	<b>30-39 years</b>	<b>&lt; 30</b>	5,6369	6,69441	,950	-15,0828	26,3566
		<b>40-49</b>	3,5816	4,82499	,968	-11,3521	18,5154
		<b>50-60</b>	5,4892	4,63482	,844	-8,8560	19,8343

		<b>&gt; 60</b>	10,5918	4,82499	,308	-4,3419	25,5256
	<b>40-49 years</b>	<b>&lt; 30</b>	2,0553	5,95843	,998	-16,3865	20,4971
		<b>30-39</b>	-3,5816	4,82499	,968	-18,5154	11,3521
		<b>50-60</b>	1,9075	3,48846	,990	-8,8895	12,7046
		<b>&gt; 60</b>	7,0102	3,73742	,476	-4,5574	18,5778
	<b>50-60 years</b>	<b>&lt; 30</b>	,1477	5,80551	1,00	-17,8208	18,1162
		<b>30-39</b>	-5,4892	4,63482	,844	-19,8343	8,8560
		<b>40-49</b>	-1,9075	3,48846	,990	-12,7046	8,8895
		<b>&gt; 60</b>	5,1027	3,48846	,710	-5,6944	15,8997
	<b>More than 60</b>	<b>&lt; 30</b>	-4,9549	5,95843	,952	-23,3967	13,4869
		<b>30-39</b>	-10,5918	4,82499	,308	-25,5256	4,3419
		<b>40-49</b>	-7,0102	3,73742	,476	-18,5778	4,5574
		<b>50-60</b>	-5,1027	3,48846	,710	-15,8997	5,6944
<b>* The mean difference is significant at the .05 level.</b>							

## Appendix E

**Multiple comparisons of duration of diabetes and the QOL domains among the diabetic refugees and non-refugees by using Scheffe test**

QOL domains	Duration of diabetes	Duration of diabetes	Mean Difference	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Physical domain	One year ago	2-5 yrs ago	-9,0359	5,82723	,494	-25,3972	7,3254
		6-10 yrs ago	2,9514	5,78291	,967	-13,2855	19,1883
		> 10 yrs ago	18,3333(*)	5,98588	,026	1,5266	35,1401
	2-5 years ago	One yr ago	9,0359	5,82723	,494	-7,3254	25,3972
		6-10 yrs ago	11,9873(*)	3,17323	,003	3,0777	20,8969
		> 10 yrs ago	27,3692(*)	3,52960	,000	17,4590	37,2794
	6-10 years ago	One yr ago	-2,9514	5,78291	,967	-19,1883	13,2855
		2-5 yrs ago	-11,9873(*)	3,17323	,003	-20,8969	-3,0777
		> 10 yrs ago	15,3819(*)	3,45595	,000	5,6786	25,0853
	More than 10 years ago	One yr ago	-18,3333(*)	5,98588	,026	-35,1401	-1,5266
		2-5 yrs ago	-27,3692(*)	3,52960	,000	-37,2794	-17,4590
		6-10 yrs ago	-15,3819(*)	3,45595	,000	-25,0853	-5,6786
Psychological domain	One year ago	2-5 yrs ago	-7,0179	5,66217	,674	-22,9158	8,8799
		6-10 yrs ago	1,7083	5,61911	,993	-14,0686	17,4853
		> 10 yrs ago	17,8438(*)	5,81633	,025	1,5130	34,1745
	2-5 years ago	One year ago	7,0179	5,66217	,674	-8,8799	22,9158
		6-10 yrs ago	8,7263(*)	3,08335	,047	,0691	17,3835
		> 10 yrs ago	24,8617(*)	3,42963	,000	15,2322	34,4912
	6-10 years ago	One yr ago	-1,7083	5,61911	,993	-17,4853	14,0686
		2-5 yrs ago	-8,7263(*)	3,08335	,047	-17,3835	-,0691
		> 10 yrs ago	16,1354(*)	3,35806	,000	6,7069	25,5640
	More than 10 years ago	One yr ago	-17,8438(*)	5,81633	,025	-34,1745	-1,5130
		2-5 yrs ago	-24,8617(*)	3,42963	,000	-34,4912	-15,2322
		6-10 yrs ago	-16,1354(*)	3,35806	,000	-25,5640	-6,7069
Social domain	One year ago	2-5 yrs ago	-,4782	4,41889	1,000	-12,8853	11,9289
		6-10 yrs ago	5,9861	4,38529	,602	-6,3266	18,2988
		> 10 yrs ago	16,0104(*)	4,53920	,007	3,2655	28,7553
	2-5 years ago	One yr ago	,4782	4,41889	1,000	-11,9289	12,8853
		6-10 yrs ago	6,4643	2,40632	,067	-,2920	13,2206
		> 10 yrs ago	16,4886(*)	2,67656	,000	8,9736	24,0037

	<b>6-10 years ago</b>	<b>One yr ago</b>	-5,9861	4,38529	,602	-18,2988	6,3266
		<b>2-5 yrs ago</b>	-6,4643	2,40632	,067	-13,2206	,2920
		<b>&gt; 10 yrs ago</b>	10,0243(*)	2,62071	,002	2,6661	17,3826
	<b>More than 10 years ago</b>	<b>One year ago</b>	-16,0104(*)	4,53920	,007	-28,7553	-3,2655
		<b>2-5 years ago</b>	-16,4886(*)	2,67656	,000	-24,0037	-8,9736
		<b>6-10 yrs ago</b>	-10,0243(*)	2,62071	,002	-17,3826	-2,6661
<b>Environmental domain</b>	<b>One year ago</b>	<b>2-5 years ago</b>	-8,1506	5,55323	,542	-23,7426	7,4413
		<b>6-10 yrs ago</b>	-2,1250	5,51100	,985	-17,5984	13,3484
		<b>&gt; 10 yrs ago</b>	13,4896	5,70442	,135	-2,5269	29,5061
	<b>2-5 years ago</b>	<b>One year ago</b>	8,1506	5,55323	,542	-7,4413	23,7426
		<b>6-10 yrs ago</b>	6,0256	3,02402	,266	-2,4650	14,5163
		<b>&gt; 10 yrs ago</b>	21,6402(*)	3,36364	,000	12,1960	31,0844
	<b>6-10 years ago</b>	<b>One year ago</b>	2,1250	5,51100	,985	-13,3484	17,5984
		<b>2-5 years ago</b>	-6,0256	3,02402	,266	-14,5163	2,4650
		<b>&gt; 10 yrs ago</b>	15,6146(*)	3,29345	,000	6,3675	24,8617
	<b>More than 10 years ago</b>	<b>One year ago</b>	-13,4896	5,70442	,135	-29,5061	2,5269
		<b>2-5 years ago</b>	-21,6402(*)	3,36364	,000	-31,0844	-12,1960
		<b>6-10 yrs ago</b>	-15,6146(*)	3,29345	,000	-24,8617	-6,3675
<b>Global value</b>	<b>One year ago</b>	<b>2-5 years ago</b>	-5,9615	5,06013	,709	-20,1690	8,2460
		<b>6-10 yrs ago</b>	2,5556	5,02165	,968	-11,5439	16,6550
		<b>&gt;10 years ago</b>	17,4792(*)	5,19790	,011	2,8848	32,0735
	<b>2-5 years ago</b>	<b>One year ago</b>	5,9615	5,06013	,709	-8,2460	20,1690
		<b>6-10 yrs ago</b>	8,5171(*)	2,75551	,024	,7804	16,2538
		<b>&gt; 10 yrs ago</b>	23,4407(*)	3,06497	,000	14,8351	32,0463
	<b>6-10 years ago</b>	<b>One year ago</b>	-2,5556	5,02165	,968	-16,6550	11,5439
		<b>2-5 years ago</b>	-8,5171(*)	2,75551	,024	-16,2538	-,7804
		<b>&gt; 10 yrs ago</b>	14,9236(*)	3,00101	,000	6,4976	23,3497
	<b>More than 10 years ago</b>	<b>One year ago</b>	-17,4792(*)	5,19790	,011	-32,0735	-2,8848
		<b>2-5 years ago</b>	-23,4407(*)	3,06497	,000	-32,0463	-14,8351
		<b>6-10 yrs ago</b>	-14,9236(*)	3,00101	,000	-23,3497	-6,4976
* The mean difference is significant at the .05 level.							

## Appendix F

**Post Hoc multiple comparisons (Scheffe test) among the significant differences between the complications of diabetes among the case and control.**

QOL domains	Complications of Diabetes	Complications of Diabetes	Mean Difference	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Physical domain	Retinopathy	Nephropathy	-1,2224	3,81051	1,000	-13,9670	11,5222
		Neuropathy	10,7064	3,76229	,154	-1,8769	23,2897
		Diabetic foot	10,7663	3,49288	,093	-,9159	22,4485
		Nothing	-32,3589(*)	2,46999	,000	-40,6200	-24,0978
		> one complication	24,6113(*)	2,85041	,000	15,0779	34,1447
	Nephropathy	Retinopathy	1,2224	3,81051	1,000	-11,5222	13,9670
		Neuropathy	11,9288	4,39925	,198	-2,7849	26,6424
		Diabetic foot	11,9887	4,17118	,145	-1,9622	25,9395
		Nothing	-31,1366(*)	3,36146	,000	-42,3792	-19,8939
		> one complication	25,8337(*)	3,65012	,000	13,6256	38,0418
	Neuropathy	Retinopathy	-10,7064	3,76229	,154	-23,2897	1,8769
		Nephropathy	-11,9288	4,39925	,198	-26,6424	2,7849
		Diabetic foot	,0599	4,12717	1,000	-13,7438	13,8636
		Nothing	-43,0653(*)	3,30670	,000	-54,1249	-32,0058
		> one complication	13,9049(*)	3,59975	,012	1,8652	25,9446
	Diabetic foot	Retinopathy	-10,7663	3,49288	,093	-22,4485	,9159
		Nephropathy	-11,9887	4,17118	,145	-25,9395	1,9622
		Neuropathy	-,0599	4,12717	1,000	-13,8636	13,7438
		Nothing	-43,1252(*)	2,99659	,000	-53,1476	-33,1029
		> one complication	13,8450(*)	3,31715	,004	2,7505	24,9395
	Nothing	Retinopathy	32,3589(*)	2,46999	,000	24,0978	40,6200
		Nephropathy	31,1366(*)	3,36146	,000	19,8939	42,3792
		Neuropathy	43,0653(*)	3,30670	,000	32,0058	54,1249
		Diabetic foot	43,1252(*)	2,99659	,000	33,1029	53,1476
		> one complication	56,9702(*)	2,21454	,000	49,5635	64,3770
More than one complication	Retinopathy	-24,6113(*)	2,85041	,000	-34,1447	-15,0779	
	Nephropathy	-25,8337(*)	3,65012	,000	-38,0418	-13,6256	
	Neuropathy	-13,9049(*)	3,59975	,012	-25,9446	-1,8652	
	Diabetic foot	-13,8450(*)	3,31715	,004	-24,9395	-2,7505	
	Nothing	-56,9702(*)	2,21454	,000	-64,3770	-49,5635	



<b>Psychological domain</b>	<b>Retinopathy</b>	<b>Nephropathy</b>	-5,8392	4,21380	,860	-19,9326	8,2543
		<b>Neuropathy</b>	10,5084	4,16048	,273	-3,4067	24,4235
		<b>Diabetic foot</b>	8,2513	3,86255	,473	-4,6673	21,1699
		<b>Nothing</b>	-29,6624(*)	2,73140	,000	-38,7978	-20,5270
		<b>&gt; one complication</b>	20,7076(*)	3,15208	,000	10,1652	31,2500
	<b>Nephropathy</b>	<b>Retinopathy</b>	5,8392	4,21380	,860	-8,2543	19,9326
		<b>Neuropathy</b>	16,3476(*)	4,86484	,048	,0767	32,6185
		<b>Diabetic foot</b>	14,0905	4,61263	,099	-1,3368	29,5178
		<b>Nothing</b>	-23,8232(*)	3,71722	,000	-36,2558	-11,3907
		<b>&gt; one complication</b>	26,5468(*)	4,03643	,000	13,0466	40,0469
	<b>Neuropathy</b>	<b>Retinopathy</b>	-10,5084	4,16048	,273	-24,4235	3,4067
		<b>Nephropathy</b>	-16,3476(*)	4,86484	,048	-32,6185	-,0767
		<b>Diabetic foot</b>	-2,2571	4,56397	,999	-17,5217	13,0075
		<b>Nothing</b>	-40,1708(*)	3,65666	,000	-52,4008	-27,9408
		<b>&gt; one complication</b>	10,1992	3,98073	,258	-3,1147	23,5131
	<b>Diabetic foot</b>	<b>Retinopathy</b>	-8,2513	3,86255	,473	-21,1699	4,6673
		<b>Nephropathy</b>	-14,0905	4,61263	,099	-29,5178	1,3368
		<b>Neuropathy</b>	2,2571	4,56397	,999	-13,0075	17,5217
		<b>Nothing</b>	-37,9137(*)	3,31374	,000	-48,9968	-26,8307
		<b>&gt; one complication</b>	12,4563(*)	3,66823	,044	,1876	24,7250
	<b>Nothing</b>	<b>Retinopathy</b>	29,6624(*)	2,73140	,000	20,5270	38,7978
		<b>Nephropathy</b>	23,8232(*)	3,71722	,000	11,3907	36,2558
		<b>Neuropathy</b>	40,1708(*)	3,65666	,000	27,9408	52,4008
		<b>Diabetic foot</b>	37,9137(*)	3,31374	,000	26,8307	48,9968
		<b>&gt; one complication</b>	50,3700(*)	2,44892	,000	42,1794	58,5606
<b>More than one complication</b>	<b>Retinopathy</b>	-20,7076(*)	3,15208	,000	-31,2500	-10,1652	
	<b>Nephropathy</b>	-26,5468(*)	4,03643	,000	-40,0469	-13,0466	
	<b>Neuropathy</b>	-10,1992	3,98073	,258	-23,5131	3,1147	
	<b>Diabetic foot</b>	-12,4563(*)	3,66823	,044	-24,7250	-,1876	
	<b>Nothing</b>	-50,3700(*)	2,44892	,000	-58,5606	-42,1794	
<b>Social domain</b>	<b>Retinopathy</b>	<b>Nephropathy</b>	-10,1252	4,40720	,385	-24,8654	4,6151
		<b>Neuropathy</b>	8,1697	4,35143	,620	-6,3840	22,7234
		<b>Diabetic foot</b>	2,3364	4,03982	,997	-11,1752	15,8479
		<b>Nothing</b>	-14,3266(*)	2,85677	,000	-23,8813	-4,7719
		<b>&gt; one complication</b>	8,3229	3,29675	,274	-2,7034	19,3491
	<b>Nephropathy</b>	<b>Retinopathy</b>	10,1252	4,40720	,385	-4,6151	24,8654
		<b>Neuropathy</b>	18,2949(*)	5,08812	,026	1,2772	35,3125

		<b>Diabetic foot</b>	12,4615	4,82433	,249	-3,6739	28,5969
		<b>Nothing</b>	-4,2014	3,88782	,948	-17,2045	8,8018
		<b>&gt; one complication</b>	18,4480(*)	4,22168	,002	4,3283	32,5678
	<b>Neuropathy</b>	<b>Retinopathy</b>	-8,1697	4,35143	,620	-22,7234	6,3840
		<b>Nephropathy</b>	-18,2949(*)	5,08812	,026	-35,3125	-1,2772
		<b>Diabetic foot</b>	-5,8333	4,77344	,914	-21,7985	10,1318
		<b>Nothing</b>	-22,4963(*)	3,82448	,000	-35,2876	-9,7049
		<b>&gt; one complication</b>	,1532	4,16343	1,000	-13,7718	14,0781
	<b>Diabetic foot</b>	<b>Retinopathy</b>	-2,3364	4,03982	,997	-15,8479	11,1752
		<b>Nephropathy</b>	-12,4615	4,82433	,249	-28,5969	3,6739
		<b>Neuropathy</b>	5,8333	4,77344	,914	-10,1318	21,7985
		<b>Nothing</b>	-16,6629(*)	3,46582	,000	-28,2547	-5,0712
		<b>&gt; one complication</b>	5,9865	3,83658	,786	-6,8453	18,8183
	<b>Nothing</b>	<b>Retinopathy</b>	14,3266(*)	2,85677	,000	4,7719	23,8813
		<b>Nephropathy</b>	4,2014	3,88782	,948	-8,8018	17,2045
		<b>Neuropathy</b>	22,4963(*)	3,82448	,000	9,7049	35,2876
		<b>Diabetic foot</b>	16,6629(*)	3,46582	,000	5,0712	28,2547
		<b>&gt; one complication</b>	22,6494(*)	2,56131	,000	14,0829	31,2159
	<b>More than one complication</b>	<b>Retinopathy</b>	-8,3229	3,29675	,274	-19,3491	2,7034
		<b>Nephropathy</b>	-18,4480(*)	4,22168	,002	-32,5678	-4,3283
		<b>Neuropathy</b>	-,1532	4,16343	1,000	-14,0781	13,7718
		<b>Diabetic foot</b>	-5,9865	3,83658	,786	-18,8183	6,8453
		<b>Nothing</b>	-22,6494(*)	2,56131	,000	-31,2159	-14,0829
<b>Environmental domain</b>	<b>Retinopathy</b>	<b>Nephropathy</b>	-10,6203	4,45468	,340	-25,5193	4,2788
		<b>Neuropathy</b>	7,2330	4,39831	,745	-7,4775	21,9435
		<b>Diabetic foot</b>	5,2123	4,08335	,897	-8,4448	18,8694
		<b>Nothing</b>	-28,8627(*)	2,88755	,000	-38,5204	-19,2051
		<b>&gt; one complication</b>	15,9317(*)	3,33227	,000	4,7866	27,0768
	<b>Nephropathy</b>	<b>Retinopathy</b>	10,6203	4,45468	,340	-4,2788	25,5193
		<b>Neuropathy</b>	17,8533(*)	5,14294	,036	,6523	35,0543
		<b>Diabetic foot</b>	15,8326	4,87632	,064	-,4767	32,1418
		<b>Nothing</b>	-18,2424(*)	3,92971	,001	-31,3857	-5,0992
		<b>&gt; one complication</b>	26,5520(*)	4,26717	,000	12,2801	40,8239
	<b>Neuropathy</b>	<b>Retinopathy</b>	-7,2330	4,39831	,745	-21,9435	7,4775
		<b>Nephropathy</b>	-17,8533(*)	5,14294	,036	-35,0543	-,6523
		<b>Diabetic foot</b>	-2,0207	4,82487	,999	-18,1579	14,1165
		<b>Nothing</b>	-36,0957(*)	3,86569	,000	-49,0249	-23,1666

		<b>&gt; one complication</b>	8,6987	4,20829	,512	-5,3763	22,7737
<b>Diabetic foot</b>		<b>Retinopathy</b>	-5,2123	4,08335	,897	-18,8694	8,4448
		<b>Nephropathy</b>	-15,8326	4,87632	,064	-32,1418	,4767
		<b>Neuropathy</b>	2,0207	4,82487	,999	-14,1165	18,1579
		<b>Nothing</b>	-34,0750(*)	3,50317	,000	-45,7917	-22,3584
		<b>&gt; one complication</b>	10,7194	3,87792	,180	-2,2506	23,6894
<b>Nothing</b>		<b>Retinopathy</b>	28,8627(*)	2,88755	,000	19,2051	38,5204
		<b>Nephropathy</b>	18,2424(*)	3,92971	,001	5,0992	31,3857
		<b>Neuropathy</b>	36,0957(*)	3,86569	,000	23,1666	49,0249
		<b>Diabetic foot</b>	34,0750(*)	3,50317	,000	22,3584	45,7917
		<b>&gt; one complication</b>	44,7944(*)	2,58891	,000	36,1356	53,4532
<b>More than one complication</b>		<b>Retinopathy</b>	-15,9317(*)	3,33227	,000	-27,0768	-4,7866
		<b>Nephropathy</b>	-26,5520(*)	4,26717	,000	-40,8239	-12,2801
		<b>Neuropathy</b>	-8,6987	4,20829	,512	-22,7737	5,3763
		<b>Diabetic foot</b>	-10,7194	3,87792	,180	-23,6894	2,2506
		<b>Nothing</b>	-44,7944(*)	2,58891	,000	-53,4532	-36,1356

## Appendix G

### Interview Transcription

#### **Demographic data and health profile:**

A 55 years old male, lives with his family in a poor house in Anuseirat refugee camp in Gaza strip. His educational attainment is only tertiary school; he said “I had to quit my education to help my father in his work in Israel to support the family”. He is married, has 5 children. Financially, he supports his 5 children, his mother in addition to his unemployed brother. Till 1995 he was working in Israel as a builder but since that time he was not allowed to take the permission to enter Israel, “I did not know why the Israeli authorities took my work permission, I did not do any thing against them” he said. He works irregularly in Gaza strip in building houses but unable to gain enough money to support his family; he said “I work 2 or 3 months and when it is finished I have to wait another 2-3 months to find an offer, in Gaza strip there are no good possibilities to find a good work, sometimes I have to borrow money from my friends to support my family”.

He was diagnosed with Type 2 diabetes for 13 years, takes insulin and pills to control the diabetes but he is fully compliant with his therapeutic plan; he said: “Frequently, I forget to take the prescribed insulin or pills and sometimes I am too lazy to take them, and often I don’t have enough money to buy them”. Regarding the dietary regime, he continued: “It is very difficult for me to quit eating sugar or sweets and I don’t have enough money to cook two menus, diabetic diet and the normal diet”. He suffers from diabetic foot.

#### **Items of the WHOQOL questionnaire:**

##### **1. How would you rate your quality of life, and why?**

He answered: “My quality of life is very poor, I still live in an extended family house, I don’t have a good job, I don’t have enough money to support my family, even the medication, sometimes I can not buy them”. He continued: “The life as a refugee in the camp is very hard, the houses are stick to each other, we don’t have good clinics or hospitals, we can not easily traveled to the hospitals in Gaza because of the checkpoints near Natzarim settlement, sometimes I had to walk 4-5 kilometers to avoid the checkpoint and because of the strict seize around the camp”.

Regarding diabetes, he said: “The diabetes has worsened my life and added another overload. Honestly, it is not easy for me to keep eating diabetic diet; sometimes I am invited to a wedding parties in which normal lunch (rice, meat, and sweets) are served. This situation creates a conflict for me because I know that I have to carry out social roles and to share the others in eating and at the same time I have to comply with the therapeutic diet. This is a small example how diabetes negatively affected my life”. “And not forget that Sugar Disease (he means diabetes) can causes problems in the kidneys, eyes and the nerves; and now I have already a small infection in my link foot”.

##### **2. How satisfied are you with your health, and why?**

He said: “I am not satisfied with my health at all because I don’t know what will happen to me in the next years, also sometimes I do not know what to do more to control the sugar. Even the

UNRWA clinic in the camp does not provide a good care, it is always full and I have to wait several hours to see the doctor for five or ten minutes and I can not measure my sugar at home because I do not have “glucometer”. And it is very expensive to go to a private doctor. Now I have an infection in my big toe and I don not have enough money to buy the compresses, the gauzes and the ointment”.

### **3. How much do you need any medical treatment to function in your daily life?**

He answered: “I need every day about 24-36 insulin units for my (Sugar), this depends on the level of sugar in the blood but the problem for me is that I do not measure my blood sugar because I do not have the equipment to do this, instead, I guess my self and I inject myself based on my guess. Many times, I forget or not willing to take the medication”.

### **4. How much do you enjoy life, and why?**

He said: “How can I enjoy my life and I suffer from diabetes. Actually, I am always worried that I will die earlier because diabetes is a life-long disease and very difficult to control. Now I have diabetic foot, who knows which complications will appear in the future. I know many diabetic patients in the camps sitting on wheelchairs and I know others who died early”. He continued: “we, as refugees living in the camps, there is no chance for us to enjoy life. We are not allowed to leave Gaza strip to other countries even for medical purposes, and sometimes we are not allowed to leave this camp under a security rationalizations, and in case you are allowed to freely travel you do not have enough money to do so...The only thing which alleviate our suffering is our faith in God, that all of these suffering that we are going through is considered as an exam for us in this life and if we afford this we will take our prize in the day after”.

### **5. To what extent do you feel your life to be meaningful, and why?**

He said: “In my life, there is nothing to let me think that the life has a meaning. Every thing around remind me with the poverty and hopelessness. My health, my economic situation, and the daily suffering which we experience in our lives made it very difficult to find any meaning for the life. I feel myself different from the others because I have to follow strict diet, sometimes I feel dizzy while sitting with people because of the sugar problems which frustrate me”. However, there is only one thing which gives me a ray of hope, namely, my religious values and faith in God, which necessitate that the person must always be satisfied with the disease and with his life conditions. I perceive my disease and my hard life as an exam from God, and I am satisfied with God’s will”.

### **6. How safe do you feel in your daily life?**

He answered while laughing: “What type of safety you are taking about..!! Day and night we hear the voices of the guns and the Helicopters bombardment. We don’t feel safe even when we sit at our homes. Many times the Apache Helicopters has attacked with missiles a civilized and innocent people in the middle of the camp in order to kill a (wanted) person. You remember before two years exactly before Ramadan Aid (Fasting fest) when the Helicopters killed 15 innocent persons in Annusirat camp including children and the Doctor of the MOH clinic in the camp and after that “they” apologized saying that it was a technical failure. If you want to go Khan Yunis city or Rafah which they are only 15 Kilometers away, you need at least 4-6 hours

(when you are lucky) because of the checkpoints and the Israeli strict control measures. And very often you are not allowed to pass. Approximately, in every Palestinian house, there is a wounded person, a martyr or a prisoner. All of these stressors increase my sugar and I am not able to concentrate to take my medications or to regulate my diet.”

### **7. How healthy is your physical environment?**

He said: “As you see, the houses are very small, compacted with each other and poor ventilated. The rooms are not good furnished. In winter water passes through the ceiling. In my home live, for example, about 8 persons and it is only 70 m<sup>2</sup>. There is no healthy sewage system serving the camp and most of the roads are not surfaced. For example, over 60.000 refugees live in Annuseirat camp whose area is less than 10 square kilometer without appropriate infrastructure. The water we drink is not clean and the too much old cars add more pollution to the air. Moreover, lack of health services in the camps makes our situation very bad.”.

### **8. Do you have enough energy for everyday life?**

He said: “Sometimes when my (sugar) is normal I feel my self very healthy and full-energetic, and sometimes when my sugar is low or high related to stress I feel myself very tired and sometimes depressed. But, since the appearance of the infection in my foot (he means the diabetic foot), I tried not to move too much in order not to worsen the wound. This, in turn, let me feel depressed”.

### **9. Are you able to accept your bodily appearance, why?**

He said: “Before the complication, every thing was normal for me and I perceived my body image as normal but after the appearance of the infection in my foot I was not able to walk normally and I go lamely (little claudication). In addition, the sites of insulin injection in my abdomen and legs distorted the appearance of the skin. Accordingly, I can not wear short trousers. However, I tried always to persuade my self and to perceive all of these problems as an exam from God and I have to pass this exam in return for the reward in the other life.”

### **10. Have you enough money to meet your needs?**

He said: “Before 1995 I was working in Israel in the construction (as a builder) and I have earned enough money, but after that and suddenly the Israeli have cancelled my permission (along with many workers) to enter Israel. Since that time, I am trying to find a durable job but without success. Sometimes I work 3-4 months and sometimes I do not find any job for 6 months. The best monthly income I have ever gained since 1995 was 2500 INS (about 550 USD) and this was only for a short-term job. Now I have 5 children and I have to support them financially in addition to my mother who lives with me at the same house. Sometimes I receive some irregular aids from charitable institutions and associations but these aids are not enough. Very often, I have lost good work offer in other cities like Rafah or Khan Yunis in the south because I can't reach such areas because of the closures and “Abo Holy” checkpoints.” He added: “the situation for me has changed since I had this complication (Diabetic foot), because I can not work any more.”

**11. How available to you is the information that you need to manage your disease?**

He answered: “Honestly, I do not know too much about diabetes. I did not read any book or bulletins about it. I heard from other diabetic people that it causes so and so and it is controlled by insulin and pills in addition to diet therapy, but what are the causes or the consequences I do not possess much information about it. When we go to the UNRWA clinic in the camp, we find huge numbers of diabetic patients and other patients and we have to wait at least 4-6 hours to see the general doctor for very short time. It is impossible to discuss with him your disease because he has not enough time to do so. Our TV and media talk always about the political situation and there is no any space to discuss the health issues.”

**12. To what extent do you have the opportunity for leisure activities, and why?**

He said joking: “When we find bread to eat, then we can think about it”. “We don not have here in the camps facilities for leisure time and if we want to go to Gaza to spent a good time there, we need money!! The only thing we find it accessible and cheap is to go to the seashore in the summer. I tried to spend my time in the big mosque in the camps reading Koran or listening to a statement from Sheik.” he continued.

**13. How satisfied are you with your ability to get around and to perform your daily living activities, and why?**

He said: “I am not satisfied at all with my movement because of the infection in my foot and the little claudication. Sometimes the sugar is low or high and I feel dizzy and I can not serve myself and I ask for help. In the past I was able to walk 5 to 10 kilometers without feeling tired but now I can not do this any more.”

**14. How satisfied are you with your sleep, and why?**

“So and so” he replied. “When I feel pain in my foot I can not sleep but when I take pain medications (he means analgesics) I can sleep well. However, sometimes I have low blood sugar and I sweat so I can not sleep and sometimes I had to go urinate 2 or three times in the night. All of these things interfere with my sleep pattern”. He continued: “Do not forget that we live in a camp near the Israeli settlement of Netzarim, Almost every night, we hear fire exchange, military incursions and missile attacks, which interferes with sleeping.

**15. How satisfied are you with your personal relationships and with the support you get from your friends?**

He said: “I am totally satisfied with my personal relationships and the support I receive from my friends, neighbors and relatives. They try always to reassure and help me regarding my disease. Also, when I face a financial difficulties they help me. We always visit each other and share the others in their happy or sad occasions such as weddings, graduation, childbirth, death and sickness. I have also a very good relations with my neighbors because our religion urges us to care for them. Regarding my family members we have a very good and harmonious relationship

in spite of the financial hardship we have. My wife and sons always helps me and support me to adhere to the therapeutic regime. However, when I am sick I can't fulfill the social obligations, instead, I send my son to share the others."

**16. How satisfied are you with your sex life, and why?**

At the beginning he was reluctant to speak about this point, but with some probing and indirect questions he said: "At the beginning of my disease (before 13 years) there were no any problems with my sexual life, but since three years I started to feel some problems such as (erectile disturbances). I feel that my sexual desire is decreasing, I don't know why!! Really, this is a very shameful for me and sometimes I feel very depressive because I can not do this thing as before. I went to a doctor several times but I feel no improvement. And this causes for me a big stress".

**17. How satisfied are you with your access to health services, and why?**

He said: "I am not satisfied with the health services provided for us by UNRWA. There is only one general doctor in the morning shift and another one for the afternoon shift for more than 100-150 patients daily. I have to wait 4-6 hours to see the doctor only for minutes. He does not perform complete examination; he just asks me about my problem and sometimes before I complete my speaking he writes the prescription. A general doctor is not enough; we need to be examined by diabetologist at least once every month. The staff there behaves with us impolitely. They do not educate us about our disease and how to deal with it in a critical situation. For example, I take the insulin and pills since long time but what are the differences between the both? I don't know. What are the side effects for insulin and what to do in case of its occurrence?!! Also I don't know".

**18. How often do you have negative feelings such as blue mood, despair, anxiety, depression?**

He said: "I experience most of these feelings very often. When I deeply think about my self and my disease and my difficult financial status, I lose my desire in the life. Sometimes I lose the hope to get out from such crises. Very often I become very quickly nervous and I do not talk with any one. All of these bad feelings make me unable to think positively about my disease and my family".