

Dedication

To my late mother and my father who taught us how to give.....

To my wife who supported me on the front line wholeheartedly.....

To my children Aseel & Baraa who taught us patience and love.....

To my brothers Yasin & Azmi who spared no effort to help.....

To all researchers who are working to improve the quality of live of patients.....

*To the Palestinian people especially the refugees who are still making life possible to face the
violations against their civil and political rights.....*

To all of them I dedicate this work

GLOSSARY

Abbreviations	Full Name
ADA	American Diabetes Association
ANOVA	Analysis of Variance
BMI	Body Mass Index
CAC	Coronary artery calcification
CDC	Centers for Disease Control and Prevention
CI	Confidence interval
DCP	Diabetes Care Profile
Dfb	Degree of freedom between groups
DFU	Diabetic foot ulcer
Dfw	Degree of freedom within groups
DM	Diabetes mellitus
DPP	Diabetes Prevention Program Research Group
DPS	Diabetes Prevention Study
DQOL	Diabetes Quality of Life Measure
ED	Erectile dysfunction
FPG	Fasting Plasma Glucose
FSD	Female Sexual Dysfunction
F-test	Fischer test
GCMHP	Gaza Community Mental Health Programme
GDP	Gross Domestic Production
GHI	Governmental Health Insurance
GNP	Gross National Product
GPs	General practitioners
GS	Gaza Strip
HALE	Health-adjusted life expectancy
HbA1c	Hemoglobin A1c test
HMIS	Health Management Information System
HRQOL	Health-related quality of life
IDDM	Insulin-dependent diabetes mellitus
IDF	International Diabetes Federation
IFG	Impaired Fasting Glucose
IGT	Impaired Glucose Tolerance
ILS	Israel New Shekels
IQOLA	International Quality of Life Assessment Project
IT	Information Technology
Mg/dl	Milligram per Deciliter
mmol/l	Millimol per Liter
MOF	Ministry of Finance
MOH	Ministry of Health
MSP	Medical services for police and general security
NCD	Non-communicable diseases
NCM	Nurse case management
NDE	New dietary education
NGO's	Non-governmental Organizations
NHANES III	Third National Health and Nutrition Examination Survey
NHI	National Institutes of Health
NIDDM	Non-insulin-dependent diabetes mellitus

OR	Odds ratio
OGTT	Oral Glucose Tolerance Test
OHAs	Oral hypoglycemic agents
OHCHR	Office of the United Nations High Commissioner for Human Rights
PCBS	Palestinian Central Bureau of Statistics
PedsQL	Pediatric Quality of Life Inventory
PG	Plasma glucose
PHC	Primary Health Care
PMA	Palestinian Monetary Authority
PMOH	Palestinian Ministry of Health
PNA	Palestinian National Authority
PTSD	Post-traumatic stress disorder
QALYs	Quality-adjusted life years
QOL	Quality of Life
SMBG	Self-monitoring of blood glucose
SPSS	Statistical Package of Social Sciences
Sq. km ²	Square Kilometers
SSB	Between-groups sum of squares
SSW	Within-groups sum of squares
UKPDS	United Kingdom Prospective Diabetes Study
UNRWA	United Nations Relief and Works Agency for Palestine refugees in the Near East
UNESCO	United Nation Education Science Cultural Organization
USA	United States of America
WB	West Bank
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
WHOQOL-BREF	World Health Organization Quality of Life- Brief Form

Executive Summary

Diabetes mellitus (DM) 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. 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. Diabetes is reaching epidemic proportions in many countries of the world as part of the "globalization" process, and the WHO predicts 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. Shocking as they are, these figures represent only clinically diagnosed diabetes, and many more cases of diabetes remain undiagnosed and untreated.

In Palestine, DM also seems to be a serious health problem among population especially the refugees. This fact could be concluded from global estimates of the WHO and by extrapolation from similar ethnogenetically population of neighboring countries. 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. About 65.5% of all Palestinian diabetics had at least one of the major complications and only 39.7% had acceptable glycemic control. 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 ≥ 60 years old constitutes about 8.2% from the total deaths in Palestine related to DM. However, in Palestine, there is under-diagnosis and under-reporting in DM as a leading cause of death. These increasing figures of the Palestinians especially the refugees who are suffering from diabetes and the associated complications are in need for special efforts to understand how diabetes mellitus affects their daily lives and how the difficult conditions of their refuge life affect the management of diabetes.

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. Therefore, this study comes as the first step to bridge this gap.

The general purpose of the study was 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. 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.

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.

To achieve these purposes, quantitative and qualitative approaches have been used. Quantitatively, a cross-sectional paired matched case-control design recommended by several researchers was adopted for this study. For this design, QOL was assessed using World Health Organization Quality of Life Questionnaire- short version (WHOQOL-BREF). It produces scores for four domains (physical health, psychological, social relationships and environment) related to quality of life in addition to two other questions related to an individual's overall perception of quality of life and an individuals' overall perception of their health.

Qualitatively, 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.

For the quantitative approach, 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. For the qualitative approach, 33 diabetic refugees were randomly selected for the interviews.

Quantitative data and calculations were assessed using SPSS system. 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) and "post-hoc multiple comparisons" especially "Scheffe post-hoc" were used to evaluate the differences in the four domains of the quality of life among the different groups. In order to evaluate the risk possibilities of having lower QOL scores of the diabetic refugees (the case group) related to effect of the refuge life and DM compared with the diabetic non-refugees (1st control group) and the non-diabetic refugees, the adjusted odds ratios (OR) with the 95% confidence intervals (CI) were calculated for the most essential variables of the 26-items WHOQOL questionnaire.

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.

The results of this study revealed significant negative effects of the DM and refuge life on the all HRQOL domains of the diabetic refugees compared with the other two control groups. The diabetic refugees were more likely to perceive their subjective QOL as poor than the diabetic non-refugees (OR, 7.06; 95% 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).

ANOVA showed also that most of the diabetic refugees reported significantly lower scores in the physical, psychological, and environmental domains in addition to the global value of the QOL. 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 also 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.

Moreover, the ANOVA and multiple comparisons showed significant effects of some of the demographic variables and disease factors on the quality of life domains such as: age, sex, employment and income status, level of education, and duration of diabetes. However, the type of diabetes did not show significant differences in QOL domains between Type 1 and Type 2 patients.

The comparison between the health services provided for the Palestinian refugees by the MOH and UNRWA in Gaza strip revealed a little improvement regarding the MOH services, but still the existing diabetes care services in Gaza strip are less than the ambitions 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.

This research presents a clear and detailed picture of the negative effect of the refuge life and DM on the QOL of the refugees and suggested a comprehensive management plan and recommendations to improve the quality of care and the quality of life not only of the refugees but also of the whole Palestinian population. These recommendations have to be implemented in the different hierarchical and administrative levels including: restructuring the health care system, revising the policy and management of diabetes, improving the disease prevention and health promotion by activating the early detection strategies, and creating a valid and reliable database of diabetes by effective and flexible reporting system.

Finally, 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.

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