

**Original Article****Perceptions of Pain and Diabetes in two very Different Groups of Patients in Greece****Maria Kontopanou,**

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**Abstract**

**Background:** Type 2 diabetes has been proven to be a complex, heterogenous disorder with a dramatically increasing prevalence worldwide. Early use of insulin in the management of poorly controlled diabetes has been recommended to prevent and reduce the long term diabetes complications. However, various factors are delaying the insulin initiation by healthcare providers and by patients themselves. One of the main barriers is psychological insulin resistance. As the Roma community is one of the most vulnerable social groups around the world, and their health status is considered to be disproportionately burdened compared with non-Roma in many European countries, the purpose of this study is to examine the different concepts regarding diabetes and pain and the psychological resistance to insulin use between Roma and non-Roma patients, for clarifying the factors creating barriers to insulin use in poorly controlled diabetes.

**Methods:** 100 patients participated in the study and were divided into two groups: 50 from the Roma community (aged 40-60 years old) and 50 of Greek origin (aged 50-70 years old). Between the two groups, there were large statistical differences in various demographics, especially smoking ( $p=0.000$ ), and level of education ( $p=0.000$ ). Roma people show a higher incidence of hyperlipidemia, hypertension and problems associated with uncontrolled type 2 diabetes. When asked if they are followed up by a doctor, most Roma patients gave a negative answer, while Greek patients answered yes ( $p = 0.000$ ), most of them preferring a private physician, in contrast to Roma patients who preferred the hospital's outpatient department ( $p = 0.000$ ).

**Results:** Regarding the responses to the questionnaires, there are large variations in scores. In the quality of life questionnaire there were few statistical significant differences between the two groups. The BIT's results were different between the two ethnic groups and with some differences between genders as well. Comparing the overall scores of the questionnaires between the two groups, we conclude that there are big differences with the Roma having higher (worse) scores in the quality of life questionnaire, and especially regarding the barriers to insulin use.

**Conclusions:** Thus, there are large differences of diabetes management with insulin between the two groups, since Roma patients feel that their diabetes deeply affect their quality of life.

**Scientific impact and future research:** Physicians could address their concerns aiming to modify their patients' misconceptions towards insulin therapy, especially for ethnic groups, such as Roma, whose promotion of health is one of the main priorities of the European Union.

**Keywords:** Diabetes, pain, psychological insulin resistance, Roma, non-Roma.

## Introduction

Diabetes is one of the main “scourges” of the contemporary era, as the number of people with diabetes, aged 20 to 79 years, from 216 countries for the years 2010 to 2030, is expected to increase to 439 million by 2030, representing an increase of 69% in people with diabetes in developed countries and a 20% increase in developing (Shaw, et al., 2010). Greece has one of the lowest levels in type 1 diabetes rates in Europe (Dacou-Voutetakis, et al., 1995, Bartsocas 1999, Lionis, et al., 2001), but not diabetes mellitus type 2 as well as its prevalence increases in Greece and ranges from 1-6% in rural areas and at 6-12% in cities (Lionis, et al., 2001; Pitsavos et al., 2003; Symeonidis, et al., 2003; Panagiotakos et al., 2008).

The disease’s multiplicity makes it difficult for initial diagnosis (DeWit, 2009) and has a significant impact on society and patients (Zimmet 2000) and as a burden the normal function of a variety of organs, it ends up being fatal. Current medications can prolong and improve the lives of patients with chronic diabetic treatment and proper management (Ignatavicius & Workman, 2008).

The initiation of insulin therapy is often one of the most difficult and important decisions that people with diabetes should get. Because the use of insulin is often accompanied by negative perceptions, both the judgment and the treatment can be emotional and practical obstacles, leading to resistance to therapy. That is why, then, the psychological insulin resistance (PIR) may be defined as the psychological resistance to the use of insulin in patients with type diabetes 2 and their physicians (Brunton et al., 2006; Riddle, 2002; UKPDS, 1995; UKPDS, 1998; UKPDS, 1999).

More specifically, for what it concerns the Greek Roma community, it is one of the most vulnerable social groups around the world and their health status is considered to be disproportionately burdened compared to the other non-Roma people (Encyclopaedia Britannica 2014; Lewis 2009). So, according to the aforementioned assumption, the purpose of this study is to examine the different concepts regarding diabetes and pain and the psychological resistance to insulin use between Roma and non-Roma patients, in order to clarify the factors that create barriers to insulin use in

poorly controlled diabetes, and draw conclusions about the source of pain in relation to the disease and the patients’ quality of life.

## Methods

### Patient Selection

The study included a hundred patients (n=100). Fifty patients belonged to Greek Roma community and the remaining fifty were of Greek origin. The Roma group comprised of 27 Roma men and 23 Roma women, whereas the Greek group consisted of 24 Greek men and 26 Greek women. Roma were interviewed during their visit to Community Medical Centre of Municipality of Agrinio by personal interview. The remaining respondents were patients either from the University Hospital of Ioannina (25) or from private endocrine clinics of the wider area of the Municipality of Agrinio (12) that were questioned during their visit or completed the questionnaire on their own. Age ranged between 40-60 years in the Roma group and 50-70 in the Greek group, with a statistical significant difference ( $p = 0.004$ ) between the two groups. Height and weight were within normal limits without outliers.

### Data Collection

The survey was conducted using a questionnaire through quantitative values and the use of well-structured and weighted questionnaires as BIT and the Brief version of DQOL. These questionnaires were preferred because of their widespread use and recognition by the international community. We carried out a non-probability sampling, based on the following inclusion criteria:

- a) only diabetic patients were selected to answer the questionnaire,
- b) verbal consent was required in order to participate in the research following analytic explanation of the purpose of the survey,
- c) ability to communicate in Greek and mental competence required,
- d) absence of therapeutic or diagnostic procedure that might affect their psychological condition,
- e) absence of a severe illness leading to inability to complete the questionnaire leading to inability to complete the questionnaire.

Primary data collection was held by quantitative research and the use of questionnaires with personal interviews for all Roma patients in the

field of Community Medical Center of Agrinio and for the Greek patients in the wider region of Agrinio or the University Hospital of Ioannina, as mentioned above and discussed below.

The questionnaires included qualitative questions (hierarchical-nominal and spaced-ordinal) and quantitative variables (scale). The questions were related to the demographic and social characteristics of the patients, aiming to detect their satisfaction or dissatisfaction, originating from health care providers and administrative services on one hand, and the hospital's infrastructure during their arrival, stay and departure from it, on the other. An initial explanation of the purpose of research was then followed by the interview process except in certain cases where the patients completed the questionnaires themselves.

To carry out this survey, necessary approvals by the Scientific Committee of the hospital were secured, after submitting the research protocol to the hospital's Board and to each clinic's Director. Patients were informed on the purpose of the investigation prior to submission. All data were considered confidential and anonymity of their personal data was maintained. Patient participation was voluntary.

### Statistical Analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) Version 17 (SPSS, Inc. Chigago IL, USA).

The analyses performed for this research were descriptive statistics for data detailed analysis

and the Kruskal-Wallis test, as the main method of statistical analysis.

Parametric One-way ANOVA was used, because the data is non-parametric, as well as the Mann-Whitney test for means and for a possible connection of test variables.

In order to confirm the significant differences shown in the results section, it was necessary to examine possible relationships between factors that are statistically justified, and, if possible, to quantify them.

To this purpose, the data were further analyzed by measuring the non-parametric correlation coefficient Spearman's Rho Correlation test with significance limit of  $p < 0.01$ .

For the statistical evaluation of the findings, the probability  $p < 0.001$ , defined statistically significant using the Kruska-Wallis test procedure, corresponding to the parametric One-way ANOVA, because the data is non-parametric.

### Results

Overall, we observed 100 patients, 50 of Roma and 50 of Greek origin. We interviewed 27 Roma men and 23 Roma women and 24 Greek men and 26 Greek women. The majority of patients' age ranged between 40-60 years in the Roma group and 50-70 in the Greek group, showing a statistical significant difference ( $p = 0.004$ ). Height and weight were within normal range. The number of women in the sample was larger than that of men, but not to an extent which affects the analysis of results (Table 1.1).

**Table 1.1 Age by group**

GROUP							
ROMA				GREEK			
AGE				AGE			
30-40	40-50	50-60	60-70	30-40	40-50	50-60	60 -70
3	16	21	10	2	4	25	19

**Table 1.2 Smoking**

		ROMA	%	GREEK	%
Smoking in the past	YES	41	82	24	48
	NO	9	18	26	52
Smoking	YES	29	58	16	32
	NO	21	42	34	68

**Table 1.3 Marital status**

	ROMA	%	GREEK	%
Married	45	90	40	80
Divorced	0	0	2	4
Single	0	0	2	4
Widower	5	10	6	12

**Figure 1.5 Overall rating BIT depending on whether even smoke the respondents**

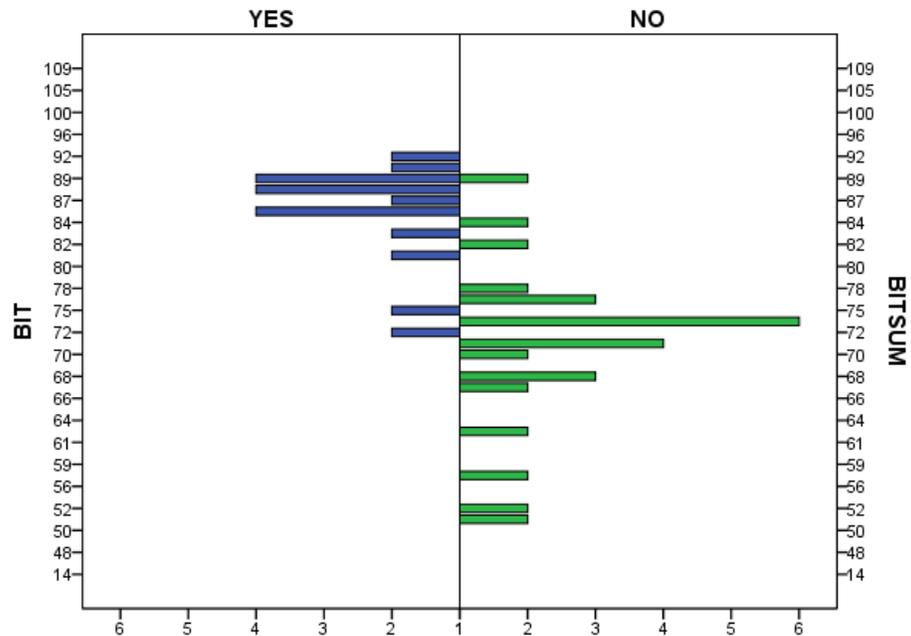


Figure 1.6 Overall rating BIT according to whether smoked the respondents

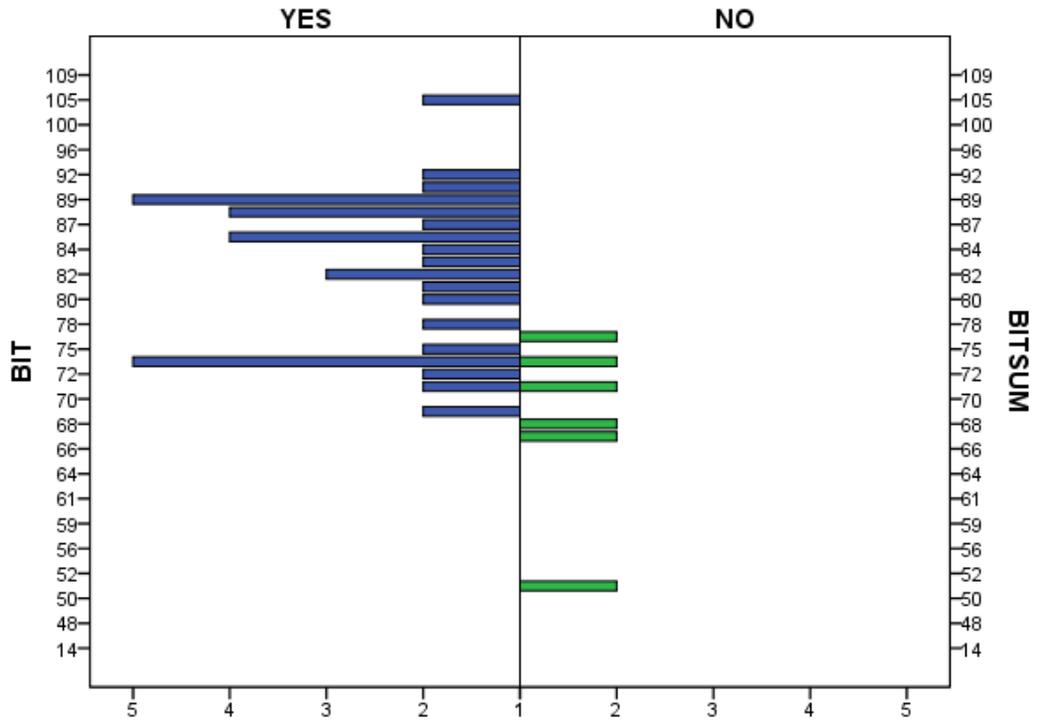


Figure 1.7 Overall rating DQOL depending on whether even smoke the respondents

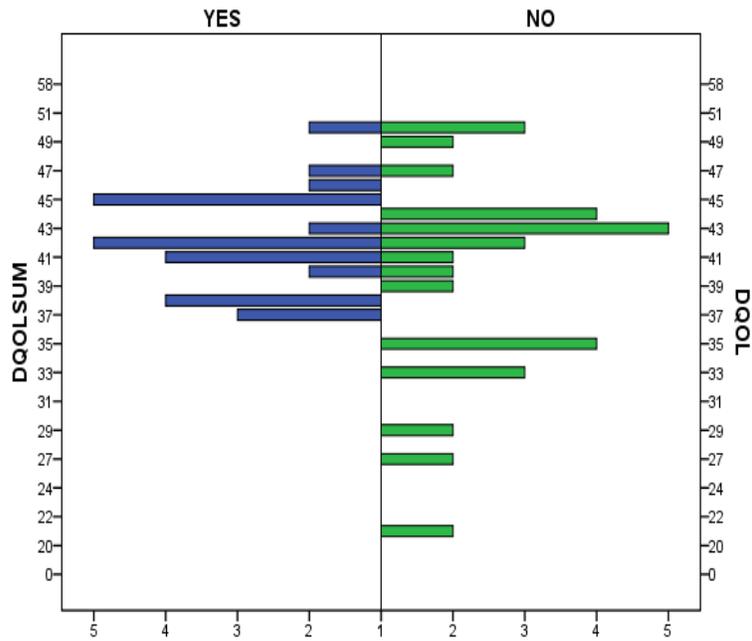


Figure 1.8 Overall rating DQOL depending on whether smoked the respondents

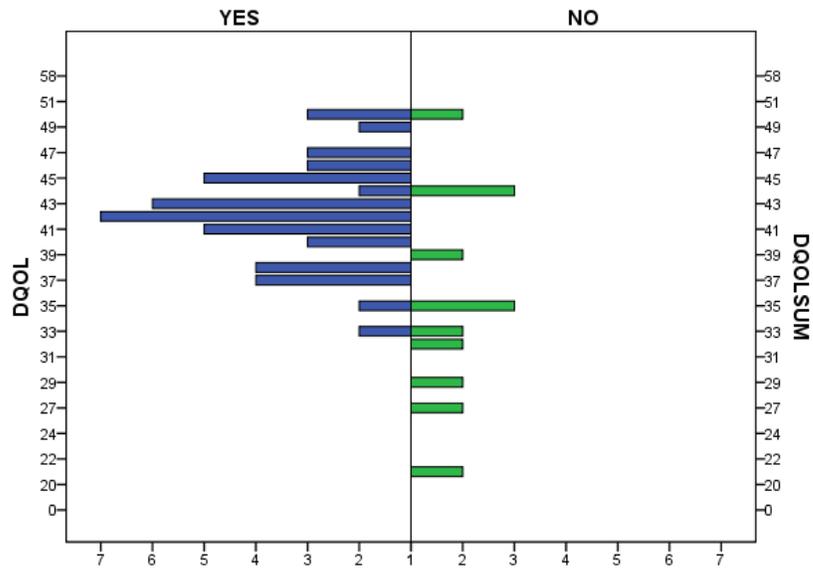


Figure 1.9 Total DQOL rating according to gender

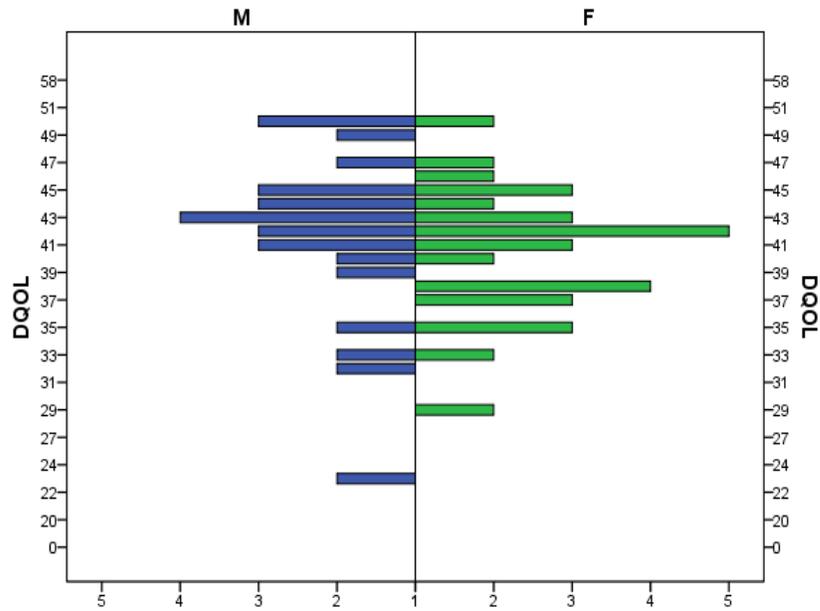


Figure 1.10 Total BIT rating according to sex

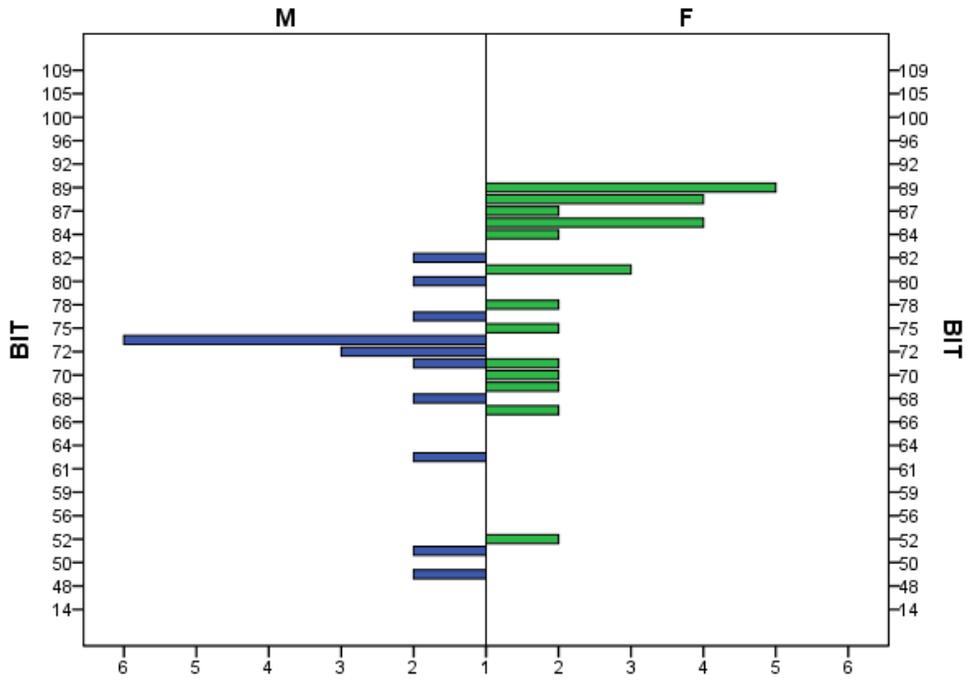


Figure 1.11 Total DQOL rating according to group

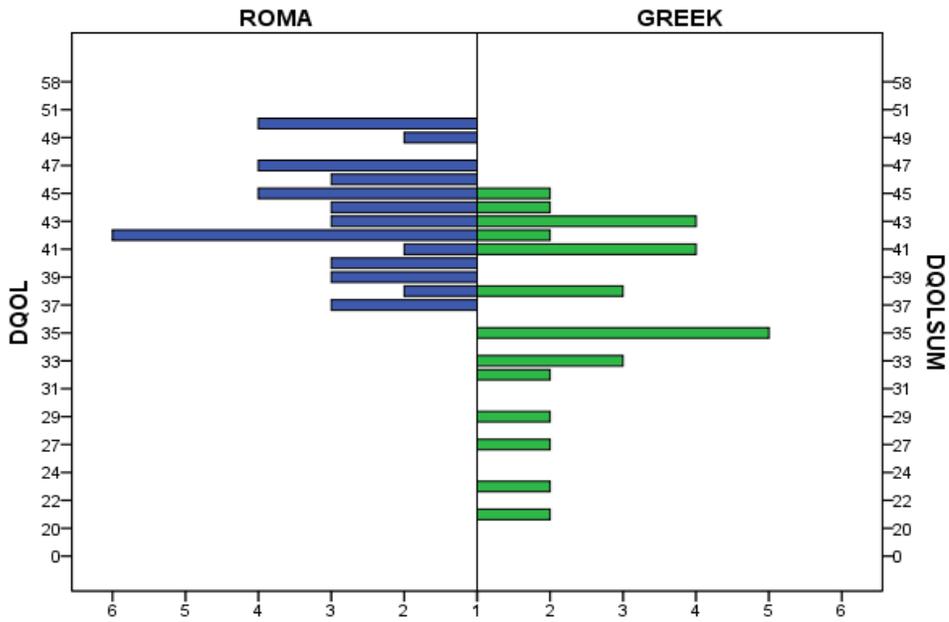


Figure 1.12 Total BIT rating according to group

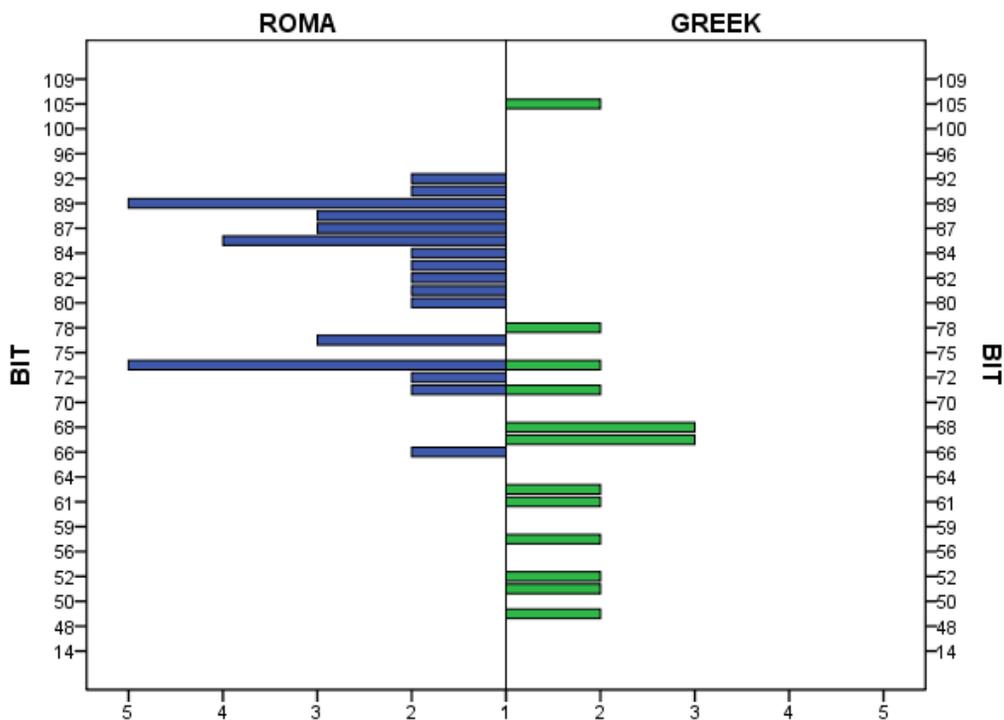


Figure 2.1 Correlations life quality and complications. The strongest are underlined. (sig. \*\*. P = 0.01.)

Correlations			GROUP	SEX	SMOKER	EX-SMOKER	DQOL	BIT
Spearman's rho	GROUP	R	1.000	<u>-0.060</u>	<u>.261**</u>	<u>.356**</u>	<u>-.530**</u>	<u>-.447**</u>
		P		.553	.009	.000	.000	.000
		N		100	100	100	100	100
	SEX	R		1.000	<u>-.364**</u>	<u>-.329**</u>	.039	<u>.289**</u>
		P			.000	.001	.704	.004
		N			100	100	100	100
	SMOKER	R			1.000	<u>.579**</u>	-.159	<u>-.321**</u>
		P				.000	.113	.001
		N				100	100	100
	EX-SMOKER	R				1.000	<u>-.300**</u>	<u>-.330**</u>
		P					.002	.001
		N					100	100
	DQOL	R					1.000	<u>.480**</u>
		P						.000

		N	100
	BIT	R	
		P	
		N	

		OR.GROUP	AGE	FAMILY	EDUCATIO N	SMOKER	EX- SMOKER	DIABETIC	HbA1c	TREATMEN T	MEDICINE	INSULIN	PHYSICIAN	BIT	DQOL
ORIGIN GROUP	GROUP	1.000	.289**	.096	.865**	.261**	.356**	.111	-.421**	.284**	.468**	.068	-.382**	-.447**	-.530**
	GROUP		.004	.343	.000	.009	.000	.277	.000	.004	.003	.811	.000	.000	.000
	GROUP		100	100	100	100	100	98	99	99	39	15	99	100	100
AGE	GROUP		1.000	.291**	.037	.154	.068	.498**	-.045	.189	.078	.092	-.348**	-.202*	-.209*
	GROUP			.003	.714	.126	.501	.000	.657	.062	.638	.743	.000	.044	.037
	GROUP			100	100	100	100	98	99	99	39	15	99	100	100
FAMILY	GROUP			1.000	.064	.023	.036	.156	-.076	-.099	-.293	.	-.071	.013	.123
	GROUP				.530	.821	.718	.126	.455	.331	.070	.	.485	.898	.221
	GROUP				100	100	100	98	99	99	39	15	99	100	100
EDUCA TION	GROUP				1.000	.129	.261**	-.098	-.454**	.160	.229	.158	-.282**	-.375**	-.467**
	GROUP					.202	.009	.337	.000	.114	.161	.575	.005	.000	.000

	GROUP					100	100	98	99	99	39	15	99	100	100
SMOKE R	GROUP					1.00	.579**	.210*	-.115	.228*	.054	-.042	-.172	-.321**	-.159
	GROUP						.000	.038	.256	.023	.745	.881	.089	.001	.113
	GROUP						100	98	99	99	39	15	99	100	100
	GROUP														
EX- SMOKE R	GROUP					1.00	.093	-.088	.171	.227	.203	-.149	-.330**	-.300**	
	GROUP							.362	.386	.090	.165	.468	.140	.001	.002
	GROUP							98	99	99	39	15	99	100	100
	GROUP							97	98	98	39	14	97	98	98
DIABETI C	GROUP						1.00	-.204*	.548**	.257	.155	-.407**	-.252*	-.104	
	GROUP								.044	.000	.119	.581	.000	.012	.308
	GROUP								98	98	38	15	97	98	98

HbA1c	GROUP							1.00	-	.021	-	.440**	.171	.258**	
	GROUP								.002	.899	.165	.000	.090	.010	
	GROUP								99	39	15	98	99	99	
TREATMENT	GROUP							1.00	-	.060	-	.482	.613**	.323**	.221*
	GROUP								.718	.069	.000	.001	.028		
	GROUP								39	15	98	99	99		
MEDICINE	GROUP								1.00	.544	.158	-.431**	-.491**		
	GROUP									.456	.338	.006	.002		
	GROUP									4	39	39	39		
INSULIN	GROUP								1.00	.	-.155	-.467			



of Roma patients had not completed even basic primary education.

### Demographic data correlating to diabetes.

Demographic questions included questions that delimit the problem for each patient and the results are shown below. The following chart depicts elaborately that important differences exists between the two groups, such as the number of years that patients knew they had diabetes. The number of years since diagnosis are less in Roma than in Greek patients, but the observed difference is not statistically significant.

Patients were asked about their most recent value of Hb1AC checked. The answers came mostly from the Greek origin group, being accurate in addition, while the majority of the Roma patients asked had no knowledge of the values measured, a difference that was found to be statistically significant ( $p < 0.001$ ).

The above question was followed by a second one, examining the forms of treatment followed by the two groups. The only difference in the answers provided by the two groups was that of the majority of Roma patients followed only a strict diet, an observation of no statistical significance. Additionally, the majority of the Roma study group received only one medication, whereas, patients of Greek origin had multiple therapeutic variations. There was a non-significant difference in the duration of insulin therapy among the two groups. The mean duration for insulin therapy in Roma was 1-5 years ( $p=0.8$ ) and for Greeks was less than a year. Table 4.6 shows the co- morbidities for the two groups.

The majority of Roma were not followed by a doctor, whereas all of the Greek patients visited a physician regularly. The doctors in outpatient hospital department followed the part of Roma group that sought medical advice, while the majority of Greek origin patients visited a private physician ( $p < 0.001$ ).

When asked about whether followed by a doctor, most Roma gave a negative answer, while all Greek origin patients answered yes ( $p < 0.001$ ), mostly treated by a private physician. The questionnaires are both LIKERT Rated. The larger the accumulated score, the more negative impact diabetes DQOL has in patient quality of life, and the limitations for insulin therapy with

BIT adoption, become stricter. Patient scores show wide variations, resulting from differences in treatment and patient origin.

It is evident that there is difference in the answers provided by the two groups on the question of whether they were former or current smokers ( $p < 0.001$ ), regardless of the grouping method used.

Figure 1.5 Overall rating BIT depending on whether even smoke the respondents. Differences between groups are observed after both groups being compared for gender. The differences are more prominent on the BIT questionnaire, showing a statistical significance value of  $p=0.004$  when gender groups are compared.

On the same questionnaire, when the two initial groups were compared for DQOL diabetes, no statistical significance was found ( $p=0.702$ ).

Regarding the quality of life, questions which were statistically significant between patients of both groups is the question for treatment satisfaction ( $p < 0.001$ ), the question for the time adjustment of diabetes ( $p < 0.001$ ), the question for the time control glucose levels ( $p < 0.001$ ), the question for physical exercise ( $p < 0.001$ ), the question about whether diabetes is an obstacle in professional career ( $p < 0.001$ ), the question for patient weight ( $p = 0.038$ ), the question for the year for health check ( $p < 0.001$ ) and the question for the knowledge on diabetes ( $p < 0.001$ ).

In the insulin use questionnaire, all questions were able to determine the differentiation between the two groups, except for question 7, which referred to insufficient injection time. Question 1 regarding fear of pain, question 2 regarding fear of injections and question 3 regarding fear of pain during glucose measurement which show significant differences among gender groups.

Spearman correlations were performed to investigate the relationships between various factors, such as quality of life, demographic and epidemiological factors. A substantial number of statistically significant correlations were observed (not published), but our analysis focused on higher degree correlations,  $R > 0.4$  to maintain a substantial effect.

Patient origin had a major effect to the questionnaire responses, with sex rather than

with smoking have no corresponding relationship. In summary, education correlates to each group's origin ( $R = 0,865$ ). HbA1c measurements correlate to the amount of medication intake ( $R = 0.468$ ) and whether they have been monitored by a public or private physician. The origin of the groups had a major correlation with the overall score of both questionnaires ( $R = -0.447, -0,530$  respectively). A significant observation between BIT insulin uptake limitations as a therapy method ( $R = 0.468$ ), and quality of life as reflected in DQOL questionnaire, which suggests that patients who believe there are limitation towards adoption of insulin therapy have worse quality of life.

### Discussion

The majority of patients with diabetes mellitus who were recently diagnosed believe that insulin would not have a positive impact on their overall health (Polonsky & Jackson 2004), and 73% of patients with type 2 diabetes, starting a training program on the use of insulin were reluctant to complete it (Okazaky et al., 1999).

PIR represents a complex set of beliefs about the meaning of insulin therapy, and is analogous to the beliefs of patients, regarding the skills needed for effective treatment, fear of injection, and the lack of information of the patient's condition. These beliefs may be influenced by past experiences, behaviors of others, perceptions of diabetes, and their understanding of the progression of their disease (Fitzgerald et al., 2000).

PIR is quite common upon initiation of insulin therapy. PIR includes, among other factors, the fear of injection and the self, hypoglycemia, and weight gain as a perceived loss of control over a patient's life, and also insulin risk management and lack of positive results associated with insulin (Polonsky et al., 2005). Patients' negative attitude upon insulin administration may exist because of possible interactions with healthcare professionals, as well as personal experience, observations, and various other psychological factors, depending on the patient. All composite elements of PIR may prevent the initiation of insulin therapy, and the increase of compliance to treatment with insulin in patients who are already using insulin.

The health-related quality of life is particularly important for chronic diseases like diabetes, for

which treatment requires constant self-monitoring that can affect a patient's way of life. Providing optimal care for diabetes treatment involves distinguishing the delicate balance between costs and benefits of disease relationship - treatment. There are many studies which have shown that the intensity of the treatment does not involve the improvement of quality of life (Hanestad & Albreksten, 1991, Jacobson, 1994, PDSG, 1999, Schiel & Muller, 1999, DCCT, 1996, Parkerson et al., 1993). For health care professionals, the main goal in treating diabetes is to help patients improve their quality of life by identifying and addressing issues related to diabetes.

There are several questionnaires that use elements of the general quality of life measurement tools, which are specifically only for diabetes, either type 1 or type 2. The questionnaires are dealing with the whole spectrum of disease, from the hospitalization until the psychological situation and knowledge of the patient in combination with quality of life. In our study we chose the Barriers to Insulin Treatment Questionnaire (BIT) and the brief Diabetes Quality of Life Measure (Brief DQOL). The BIT evaluates the obstacles perceived by the patient, when one handles their treatment by themselves. On the other hand, the brief DQOL includes questions on patient treatment satisfaction, regarding future complications or social and professional issues, etc.

The purpose of this paper is to study the perceptions of pain, psychological insulin resistance and diabetes between two very different groups of patients, Roma and Greek, and to draw conclusions about the source of pain in relation to diabetes and their quality of life.

100 patients, 50 Roma and 50 Greek origin separated by group and sex. Most Roma were aged between 40-60 years old in contrast to Greek that were 50-70, a statistically significant observation ( $p = 0.004$ ), but expected as investigations in the Greek territory also observed the same age range for Greek patients (Pitsavos, et al., 2003; Panagiotakos, et al., 2008). It is also known that the typical lifestyle of the Roma is not conducive to good health, 85% of Roma smoke regularly and an equal number are obese. In particular, the life expectancy of Roma living in the United States is 48-55 years only because of genetic

predisposition and an unhealthy lifestyle that usually involves a high sodium content, high fat diet and lack of preventive health care (Sepkowitz, 2006) and this contributed to the development of diabetes at younger ages than other racial groups exemplified by the demographics of this investigation.

There were large statistical differences in other demographics, especially smoking ( $p < 0.001$ ) while there is a great difference in the levels of education ( $p < 0.001$ ) as Roma had not by almost absolute majority even the basic primary education. Roma were prone to hyperlipidemia hypertension and problems associated with unmanaged type 2 diabetes who have a high incidence of the Roma. When asked about whether monitored by a doctor, most Roma replied no while the Greek patients answered yes ( $p < 0.001$ ) with most choosing a private physician, while Roma only the outpatient department ( $p < 0.001$ ). Regarding the substantive responses to the questionnaires are large variations in scores.

As mentioned above, especially the Roma usually wait until immediate care is required before seeking treatment and only visit the hospital when in emergency as a last resort (Bodner & Leininger, 1992; Honer, 2004). It is also not uncommon for a Roma patient to demand a specific form of treatment they have heard from their physician, regardless of whether the treatment is appropriate. (Sutherland 1992; Sepkowitz, 2006). Also Roma usually fail to meet both preventive and long-term treatments, even if they have established a relationship with a particular carrier (Honer, 2004; Goldston, 2002; Zeman, et al., 2003) that in the case of this Roma group not is certain, as in Greece moved enough.

Women were more reluctant to begin insulin treatment and indicated a greater fear of injection and social stigmatization in using insulin than men. As demonstrated in a previous study (Polonsky WH et al, 2005), ethnic minorities had greater PIR than white).

Comparing the overall scores of questionnaires for both groups, we see that there are big differences with the Roma have always higher (worse) scores and quality of life but also for the barriers to insulin. There is a good match between the questionnaires of quality of life and approach to the insulin therapy. The differences

between the two groups are statistically very significant with  $p < 0.001$  for both questionnaires.

In conclusion, it is evident from the results of this research and analysis, the difference in the treatment of diabetes and treatment with insulin in both groups of patients. Roma feel that diabetes deeply affects their quality of life. Women in general and Roma women specifically find more limitations to insulin therapy and are not willing to adopt it. Despite the fact that the promotion of the health of Roma is one of the main priorities of the European Union, a major effort by health care providers is still necessary largely because the process of integration of Roma has not achieved its objectives for the last 20 years.

### Conclusions

Finally, as a conclusion, difference in the treatment of diabetes and treatment with insulin in both patient groups is evident. The Roma feel that deeply their quality of life is considerably affected by diabetes. Women in general, and mostly Roma women find more barriers to insulin therapy and are not willing to adopt it. Despite the fact that the promotion of health of the Roma is one of the main priorities of the European Union and a large number of health-related activities have been carried out, a significant effort by health institutions is still necessary to a large extent, since the process of integration of the Roma has not achieved its objectives for the past 20 years. (Honer, 2004; Masseria, et al., 2010).

An obvious limitation of this survey is the response rate. All the respondents are from the same region of Greece. Although regarding to the PIR the literature overall is fragmentary, the most striking finding is the almost complete absence of research on Roma population. This may happen due to the difficulties of undertaking research in marginalized populations with well-developed sets of health belief such as Roma population.

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