## QUALITY OF LIFE AND PATIENT SATISFACTION WITH FAMILY PRACTICE CARE IN A ROMA POPULATION WITH CHRONIC CONDITIONS IN NORTHEAST SLOVENIA

# KAKOVOST ŽIVLJENJA V POVEZAVI S KRONIČNIMI BOLEZNIMI IN Z ZADOVOLJSTVOM Z OSKRBO ZDRAVNIKA DRUŽINSKE MEDICINE MED ROMSKIM PREBIVALSTVOM V SV SLOVENIJI

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#### **ABSTRACT**

#### Keywords:

Roma, quality of life, patient satisfaction, chronic diseases, mental health **Objectives.** Health-related quality of life (HRQoL) measures a patient's subjective experience of his or her health status. We aimed to show how the presence of chronic diseases and satisfaction with family physicians (FPs) were associated with the HRQoL of a Roma population.

**Methods.** A cross-sectional study was carried out in May 2011 on a representative sample of 650 Roma living in Prekmurje, Slovenia. The EQ-5D questionnaire was used for measuring the HRQoL of the Roma. Demographical data, 12 groups of diseases diagnosed in the last 12 months and satisfaction with FPs were included in the questionnaire.

**Results.** The response rate was 88.3% (574), of which 56.4% were female, and the average age of the participants had a mean value of  $40.2\pm12.7$  years. The presence of cardiovascular problems with risk factors for them or presence of musculoskeletal disorders were strongly associated with the presence of pain (Cramer's V=0.40 and 0.46 respectively). There was a strong association between the presence of mental disorders and anxiety and depression (Cramer's V=0.58). The average satisfaction with the family physician was 3.9 (mean $\pm1.10$ ) on a five-point Likert scale. There was no significant association between HRQoL and satisfaction with the family physician.

**Conclusions.** Roma with chronic mental health problems had the lowest HRQoL in the Roma population. More attention should be paid to this subgroup of Roma in family medicine, and interventions should be provided. High satisfaction with their FPs is not associated with the observed quality of life variables.

#### IZVLEČEK

#### Ključne besede:

Romi, kakovost življenja, zadovoljstvo bolnikov, kronične bolezni, duševno zdravje **Uvod**. Z zdravjem povezana kakovost življenja (HRQoL) je odraz pacientove subjektivne ocene lastnega zdravstvenega stanja. V naši raziskavi smo skušali ugotoviti, kakšen je vpliv nekaterih kroničnih bolezni in zadovoljstva z izbranim zdravnikom na HRQoL med romskim prebivalstvom.

**Metode**. Maja 2011 smo izvedli presečno raziskavo v reprezentativnem vzorcu 650 pomurskih Romov. HRQoL smo merili z vprašalnikom EQ-5D; vključili smo še demografske podatke, zadovoljstvo z izbranim družinskim zdravnikom in 12 bolezenskih stanj, ki so bila diagnosticirana v zadnjih 12 mesecih.

Rezultati. Odzivnost je bila 88,3-odstotna (574), 56,4% je bilo žensk in povprečna starost sodelujočih je bila 40,2+/-12,7 leta. Nizek HRQoL v skupini s srčno-žilnimi boleznimi z dejavniki tveganja zanje in kostnomišičnimi boleznimi je bil močno povezan s prisotnostjo bolečine (Cramer z V = 0,40 in 0,46). V skupini z duševnimi težavami pa je bila močna povezava nizkega HRQoL s prisotnimi znaki anksioznosti in depresije (Cramer z V = 0,58). Povprečno zadovoljstvo z zdravnikom družinske medicine je bilo 3,9 (mediana +/-1,10) na pettočkovni Likertovi lestvici. Ni bilo statistične povezave med HRQoL in zadovoljstvom z zdravnikom družinske medicine.

**Zaključki**. Romi s prisotnostjo duševnih težav imajo najnižji HRQoL v romskem prebivalstvu. Več pozornosti bi v družinski medicini morali posvetiti tej podskupini Romov. Zadovoljstvo z zdravnikom družinske medicine ni povezano z opazovanimi spremenljivkami kakovosti življenja.

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#### 1 INTRODUCTION

The Roma people in Prekmurje are an indigenous ethnic group with specific cultural characteristics, a unique language and ethnic specificities. The Roma face numerous obstacles in accessing healthcare services: these arise from poverty and low income (inability to pay for medical services); the geographical isolation of Roma settlements; the uneven distribution of healthcare institutions and staff; Roma cultural features; and communication problems between Roma and the staff at healthcare institutions (1-4).

In the last few years, research on Roma has observed that in this population non-communicable diseases are the most common cause of morbidity and mortality (5-9). This means that the increasing CVD, diabetes mellitus, COPD and mental health problems are a big burden on the Roma communities (5-9). Only a few studies have assessed the impact of ethnicity on HRQoL in non-communicable diseases, but these studies indicated that Roma ethnicity is associated with a lower mental as well as physical HRQoL (5, 10-11).

The HRQoL instrument has been developed and validated among majority populations and is not necessarily directly applicable to minorities (12). It represents people's subjective assessment of their sense of well-being and their ability to perform physical, psychological and social functions (13, 14). In the IQOLA study, it was reported that chronic diseases have an important impact on HRQoL (15). Because culture can affect the perception and interpretation of health and illness, we also expect different association between HRQoL and chronic disease in ethnic groups compared to the general population (16-18).

According to the literature, minorities typically also have a lower HRQoL than the general population (13, 17-19), and it has been shown that race and ethnicity may affect an individual's HRQoL (11). Studies conducted among various minority groups (e.g. Native Americans, Afro-Americans, African-Caribbean communities in the UK, Asian and Chinese minority groups, Albanian immigrants in Greece, Roma in Sweden and minorities in the Netherlands) focusing on the relationship between HRQoL and ethnicity indicated that the minority groups usually have a lower HRQoL (12-13, 17-18, 20-22).

In Slovenia, most Roma have chosen an FP as their primary care provider and visit them if they need to. In the past few years, interventions have been developed to increase the availability of FPs (20, 23). Some studies found an important impact of the physician on patient s HRQoL (24-26). The link between HRQoL and satisfaction with the doctor could be explained by the fact that a good doctor explains the causes of disease and methods of treatment and living with the disease. An empowered patient in this case can more easily and better cope with the disease, which can affect HRQoL (24-27).

In this study, we wanted to assess the self-reported HRQoL of a Roma population group from Prekmurje and investigate the differences between groups of people with the three most common chronic diseases. The chronic disease groups we chose were cardiovascular disease with risk fac-

tors for them (CVD), mental disorders and musculoskeletal diseases. We also wanted to determine whether patient satisfaction with their FP was associated with HRQoL. The purpose of our study was to encourage better practices by FPs when they treat Roma patients.

#### 2 METHODS

#### 2.1 Type of study

We performed a cross-sectional study, based on a field survey in May 2012, with cross-sectional data from the Prekmurje Roma population. At the time of the study, there were 3,300 Roma permanently settled in Prekmurje, an undeveloped region in the northeast part of Slovenia (28). According to the statistics in Prekmurje, 49.3% of the Roma are women (29, 30). The most common chronic diseases are: musculoskeletal disease, respiratory disease, cardiovascular disease and mental disorders (29, 30).

#### 2.2 Participants

A representative sample of 650 adults, 18-77 years old, was selected by random sampling of households in Roma settlements, with one adult selected at random per household, alternating men and women. Roma ethnicity was determined based on identification by the interviewed Roma themselves and by a member of the research team. We included 20% of the Prekmurje Roma, proportional to the population size of Roma in Prekmurje.

#### 2.3 Data collection

The HRQoL questionnaire was administered by voluntary face-to-face interview, conducted by trained community nurses. The HRQoL questionnaire is an internationally validated instrument for measurement of health related quality of life (18, 31-32). For the purpose of our study, we used it first in a pilot project in a Prekmurje Roma settlement one year before the original study. The interviews were made in the Roma settlements. The 10 trained field workers were known to the Roma through their previous work in the settlements.

#### Independent variables

**Socio-demographic background** was measured by 5 variables: sex (1 = male, 2 = female), age (in years), marital status (1 = married, 2 = single, 3 = divorced, 4 = widowed), educational attainment (1 = basic education, 2 = vocational education, 3 = upper secondary school, 4 = higher education) and activity status (1 = employed or self-employed, 2 = student, 3 = housekeeper, 4 = retired, 5 = unemployed).

Participants groups according to the presence/absence of a disease were formed by questions related to the presence of eight diagnoses or medically treated designated conditions in the past 12 months. Response options covered three conditions: 1 = yes, with drugs, 2 = yes, without drugs and 3 = No. To define focus groups, categories 1

and 2 were joined into only one category indicating presence of observed diagnosis or medically treated designated condition. We defined three main focus groups covering cardiovascular diseases with risk factors for them, diseases of the musculoskeletal system and psychiatric diseases. Cardiovascular diseases covered presence of high blood pressure, high cholesterol, myocardial infarction or chest pain and heart failure; diseases of the musculoskeletal system covered rheumatism, arthritis, low back pain and musculoskeletal diseases; and psychiatric diseases included anxiety (restlessness and depression). Respondent is classified in each group if he/she confirmed the presence of one or more diagnosis or medically treated designated condition. These focus groups are not mutually exclusive as a respondent could confirm the presence of all measured diagnoses or medically treated designated conditions.

#### Dependent variables

Health Related Quality of Life was measured by five questions related to respondents' mobility (q1), care of the self (q2), difficulty in usual daily activities (3), presence of pain (q4) and presence of anxiety or depression (q5). Response options covered three key conditions: 1 = without problems, 2 = moderate problems and 3 = severe problems.

Satisfaction groups were identified by a multi-item question on satisfaction with doctor in past 12 months. Level of satisfaction was assessed through the following 6 statements: 1. during the visit, doctor gave the feeling that he/ she had ample time for the consultation; 2. doctor was interested in your personal situation; 3. doctor helped you to tell him/her about your problems; 4. doctor listened to me; 5. doctor explained the purpose of examinations, investigations and treatment; and 6. doctor gave you enough detail on what you wanted to know about symptoms or disease. Respondents evaluated their level of satisfaction using Likert-type scale ranging from 1 = bad to 5 = excellent. For the 6-item question, a composite score was derived as an average of all six item scores. Prior factor analysis solution without rotation showed that all 6 items are associated to only one concept, with the first factor explaining 92.9% of total variance. In addition, to determine the reliability of the underlying construct, Cronbach's alpha was assessed, indicating excellent internal consistency (0.96). Final group choice criteria was established at mean value of 3 (3.00 or less = unsatisfied group; more than 3.00 = satisfied group).

#### 2.4 Analysis

In the analysis, two cross classification tables with a chisquare test were employed for testing associations between quality of life elements and implications for health conditions and the group variables, based on the data observed. 11.7% of the Roma rejected participation in the study, mostly due to lack of time or lack of interest, according to information received from the community nurses. The demographic data were analysed with basic statistical tools. The null hypothesis (H0) assumed there was no association, while the alternative hypothesis (H1) anticipated that a significant association did exist. The strength of the relationship was assessed by Cramer's V coefficient, ranging from 0 (no relationship) to 1 (perfect relationship). For interpretation of Cramer's V, varied next values and descriptors were used: 0.00-0.10 (redundant); 0.10-0.20 (weak); 0.20-0.40 (moderate); 0.40-0.60 (strong); 0.60 or higher (very strong). The statistical analysis was carried out with SPSS (Statistical package for the Social Sciences, version 21), and the level of statistical significance (P-value) was set at 0.05. The study was approved by the National Medical Ethics Committee of the Republic of Slovenia, No. 152/03/10.

#### 3 RESULTS

#### 3.1 Demographic characteristics and disease groups

The final sample consisted of 574 respondents (88.3% response rate). This comprises approximately 20% of the Prekmurje Roma population. 96.4% of the Prekmurje Roma in our sample have a chosen FP, and this percentage was mirrored in our study. Respondents were aged between 18 and 77 years; the average age was 40.2±12.1 years. 56.4% of participating Roma were female. In our sample of surveyed Roma, 72.4% were married, 78.0% had basic education and 20.0% were employed or self-employed. Socio-demographic characteristics of Roma respondents are detailed in Table 1.

The majority of Roma in the sample reported having lower back pain and musculoskeletal problems (48.6%), followed by high blood pressure (26.5%), depression (26.1%), chronic bronchitis, asthma or emphysema (26.1%), anxiety (17.4%), high cholesterol (15.3%), gastritis, ulcer (12.7%) and rheumatism, arthritis (12.5%). Considering observed disease groupings, the musculoskeletal disease group prevailed (292, 50.9%), followed by the cardiovascular disease group (203, 35.4%) and the psychiatric disease group (183, 31.9%).

#### 3.2 HRQoL and the presence of CVD with risk factors

Examination of the column percentages and standard residuals in the cardiovascular disease group crosstab (Table 2) shows that the percentage of respondents diagnosed with a cardiovascular disease without mobility problems is substantially lower, at 41.87%, than the overall average (63.41%), while that for other respondents (75.20%) is much higher than average. In addition, the proportion of respondents diagnosed with a cardiovascular disease without self-care problems is lower, at 80.30%, than the overall average (88.50%), whereas that for other respondents without CVD (92.99%) is greater than the average. The percentage of respondents diagnosed with a cardiovascular disease without pain is much lower (12.81%) than the overall average (36.41%), whereas that for those respondents without any cardiovascular disease (49.33%) is considerably above the average.

Looking further, the set of estimated Cramer's V coefficients features the association between presence of pain and the cardiovascular disease group as relatively the strongest, i.e. 0.40, demonstrating a strong association.

**Table 1.** Socio-demographic profile of respondents.

Socio-demographic characteristics		Total sample	Observed disease group		
		(n=574)	Cardiovascular with risk factors (n=203)	Musculoskeletal (n=292)	Mental problems (n=183)
Gender	Male Female	250 (43.6%) 324 (56.4%)	81 (39.9%) 122 (60.1%)	118 (40.4%) 174 (59.6%)	61 (33.3%) 122 (66.7%)
Average age (sd)		40.2 (±12.7)	47.9 (±12.1)	44.7 (±12.3)	43.8 (±13.1)
Marital status	Married Single Divorced Widowed	414 (72.4%) 112 (19.6%) 14 (2.4%) 32 (5.6%)	150 (73.9%) 22 (10.8%) 5 (2.5%) 26 (12.8%)	222 (76.0%) 36 (12.3%) 8 (2.7%) 26 (8.9%)	132 (72.5%) 28 (15.4%) 4 (2.2%) 18 (9.9%)
Educational attainment	Basic Vocational Upper secondary Higher	447 (78.0%) 55 (9.6%) 66 (11.5%) 5 (0.9%)	174 (85.7%) 14 (6.9%) 14 (6.9%) 1 (0.5%)	245 (83.9%) 27 (9.2%) 18 (6.2%) 2 (0.7%)	157 (86.3%) 8 (4.4%) 15 (8.2%) 2 (1.1%)
Activity status	Employed or self-employed Student Housekeeper Retired Unemployed	115 (20.0%) 13 (2.3%) 104 (18.1%) 53 (9.2%) 259 (50.3%)	28 (13.8%) 3 (1.5%) 41 (20.2%) 36 (17.7%) 95 (46.8%)	56 (19.2%) 2 (0.7%) 50 (17.1%) 40 (13.7) 144 (49.3%)	20 (10.9%) 3 (1.6%) 36 (19.7%) 28 (15.3%) 96 (52.5%)
Presence of disease	High blood pressure High cholesterol Diabetes mellitus Heart attack or chest pain Heart failure Rheumatic disease Lower back pain, musculoskeletal problems Chronic bronchitis, asthma	152 (26.5%) 88 (15.3%) 48 (8.4%) 43 (7.5%) 51 (8.9%) 72 (12.5%) 279 (48.6%) 150 (26.1%)	152 (74.9%) 88 (43.3%) 40 (19.7%) 43 (21.2%) 51 (25.1%) 50 (24.6%) 151 (74.4%) 81 (39.9%)	117 (40.1%) 75 (25.7%) 42 (14.4%) 38 (13.0%) 46 (15.8%) 72 (24.7%) 279 (95.5%)	72 (39.3%) 42 (23.0%) 27 (14.8%) 27 (14.8%) 30 (16.4%) 40 (21.9%) 126 (68.9%)
	or emphysema Gastritis, ulcer Anxiety Depression Cancer	73 (12.7%) 100 (17.4%) 150 (26.1%) 16 (2.8%)	42 (20.7%) 60 (29.6%) 76 (37.4%) 9 (4.4%)	61 (20.9%) 81 (27.7%) 101 (34.6%) 12 (4.1%)	41 (22.4%) 100 (54.6%) 150 (82.0%) 9 (4.9%)

Table 2. HRQoL and the cardiovascular disease group with risk factors.

HRQoL	Cardiovascular Disease Group with risk factors		
		YES	TOTAL
MOBILITY			
Without problems	279 (75.20%)	85 (41.87%)	364 (63.41%)
Moderate problems	90 (24.26%)	114 (56.16%)	204 (35.54%)
Severe problems	2 (0.54%)	4 (1.97%)	6 (1.05%)
N	371 (100%)	203 (100%)	574 (100%)
Chi-square=63.12; df=2; p<0.001 Cramer's V=0.33			
SELFCARE			
Without problems	345 (92.99%)	163 (80.30%)	508 (88.50%)
Moderate problems	24 (6.47%)	35 (17.24%)	59 (10.28%)
Severe problems	2 (0.54%)	5 (2.46%)	7 (1.22%)
N	371 (100%)	203 (100%)	574 (100%)
Chi-square=21.19; df=2; p<0.001 Cramer's V=0.19			
PRESENCE OF PAIN			
Without problems	183 (49.33%)	26 (12.81%)	209 (36.41%)
Moderate problems	175 (47.17%)	141 (69.46%)	164 (28.57%)
Severe problems	13 (3.50%)	36 (17.73%)	25 (4.36%)
N	371 (100%)	203 (100%)	574 (100%)
Chi-square=91.02; df=2; p<0.00 Cramer's V=0.40	, ,	. ,	,

HRQoL	Cardiovascular Disease Group with risk factors		
		YES	TOTAL
DIFFICULTIES IN DAILY ACTIVITIES			
Without problems	290 (78.17%)	95 (48.60%)	385 (67.07%)
Moderate problems	68 (18.33%)	96 (47.29%)	164 (28.57%)
Severe problems	13 (3.50%)	12 (5.91%)	25 (4.36%)
N	371 (100%)	203 (100%)	574 (100%)
Chi-square=59.51; df=2; p<0.001 Cramer's V=0.32	, ,	, ,	, ,
PRESENCE OF ANXIETY AND/OR DEPRESSION			
Without problems	291 (78.17%)	76 (37.44%)	295 (51.39%)
Moderate	131 (18.33%)	100 (49.26%)	231 (40.24%)
Severe problems	21 (3.50%)	27 (13.30%)	48 (8.36%)
N .	371 (100%)	203 (100%)	574 (100%)
Chi-square=27.41; df=2; p<0.001 Cramer's V=0.22	(,	, , , ,	(,

Table 3. HRQoL and the musculoskeletal system disease group.

HRQoL	Musculoskeletal System Disease Group			
	NO	YES	TOTAL	
MOBILITY				
Without problems	233 (82.62%)	131 (44.86%)	364 (63.41%)	
Moderate problems	49 (17.38%)	155 (53.08%)	204 (35.54%)	
Severe problems	0 (0.00%)	6 (2.05%)	6 (1.05%)	
N	282 (100%)	292 (100%)	574 (100%)	
Chi-square=89.51; df=2; p<0.001 Cramer's V=0.39				
CARE OF SELF				
Without problems	273 (96.81)	235 (80.48%)	508 (88.50%)	
Moderate problems	8 (2.84)	51 (17.47%)	59 (10.28%)	
Severe problems	1 (0.35)	6 (2.05%)	7 (1.22%)	
N	282 (100%)	292 (100%)	574 (100%)	
Chi-square=37.59; df=2; p<0.001 Cramer's V=0.26				
PRESENCE OF PAIN				
Without problems	165 (58.51%)	44 (15.07%)	209 (36.41%)	
Moderate problems	110 (39.01%)	206 (70.55%)	316 (55.05%)	
Severe problems	7 (2.48%)	42 (14.38%)	49 (8.54%)	
N	282 (100%)	292 (100.0%)	574 (100%)	
Chi-square=124.08; df=2; p<0.001 Cramer's V=0.46				
DIFFICULTY IN EVERYDAY ACTIVITIES				
Without problems	230 (81.56%)	155 (43.08%)	385 (67.07%)	
Moderate problems	46 (16.31%)	118 (40.41%)	164 (28.57%)	
Severe problems	6 (2.13%)	19 (6.51%)	25 (4.36%)	
N	282 (100%)	292 (100%)	574 (100%)	
Chi-square=52.82; df=2; p<0.001 Cramer's V=0.30				
PRESENCE OF ANXIETY AND/OR DEPRESSION				
Without problems	176 (62.41%)	119 (40.75%)	295 (51.39%)	
Moderate problems	91 (32.27%)	140 (47.95%)	231 (40.24%)	
Severe problems	15 (5.32%)	33 (11.30%)	48 (8.36%)	
N	282 (100%)	292 (100%)	574 (100%)	
Chi-square=27.99; df=2; p<0.001 Cramer's V=0.22				

Table 4. HRQoL and the mental health problem group.

HRQoL	M	lental health problem gro	ab dr
	NO	YES	TOTAL
MOBILITY			
Without problems	272 (69.57%)	92 (50.27%)	364 (63.41%)
Moderate problems	116 (29.67%)	88 (48.09%)	204 (35.54%)
Severe problems	3 (0.77%)	3 (1.64%)	6 (1.05%)
N	391 (100%)	183 (100%)	574 (100%)
Chi-square=20.12; df=2; p<0.001 Cramer's V=0.19			
CARE OF SELF			
Without problems	362 (92.58%)	146 (79.78%)	508 (88.50%)
Moderate problems	28 (7.16%)	31 (16.94%)	59 (10.28%)
Severe problems	1 (0.26%))	6 (3.28%)	7 (1.22%)
N	391 (100%)	183 (100%)	574 (100%)
Chi-square=23.25; df=2; p<0.001 Cramer's V=0.20			
PRESENCE OF PAIN			
Without problems	169 (43.22%)	40 (21.86%)	209 (36.41%)
Moderate problems	207 (52.94%)	109 (59.56%)	316 (55.05%)
Severe problems	15 (3.84%)	34 (18.58%)	49 (8.54%)
N	391 (100%)	183 (100%)	574 (100%)
Chi-square=48.36; df=2; p<0.001 Cramer's V=0.29			
DIFFICULTY IN EVERYDAY ACTIVITIES			
Without problems	287 (73.40%)	98 (53.55%)	385 (67.07%)
Moderate problems	96 (24.55%)	68 (37.16%)	164 (28.57%)
Severe problems	8 (2.05%)	17 (9.29%)	25 (4.36%)
N	391 (100%)	183 (100%)	574 (100%)
Chi-square=29.27; df=2; p<0.001 Cramer's V=0.23			
PRESENCE OF ANXIETY AND/OR DEPRESSION			
Without problems	275 (70.33%)	20 (10.93%)	295 (51.39%)
Moderate problems	108 (27.62%)	123 (67.21%)	231 (40.24%)
Severe problems	8 (2.05%)	40 (21.86%))	48 (8.36%)
N	391 (100%)	183 (100%)	574 (100%)
Chi-square=192.66; df=2; p<0.001 Cramer's V=0.58			

### 3.4 HRQoL and the presence of mental health problems

Examination of the percentages and residuals in the mental health problem group crosstab (see Table 4) suggested that the proportion of respondents with a psychiatric disease without mobility problems is substantially lower, at 50.27%, than the overall average (63.41%) compared to the proportion of respondents without such a disease (69.57%). Taking into consideration the presence of pain, difficulties with everyday activities and the presence of anxiety or depression, our sample data shows that in the case of the sub-category without problems, all three health condition items point to a higher proportion of respondents without a psychiatric diagnosis (43.22%; 73.40%; 70.33%) compared to those with such a diagnosis (21.86%; 53.55%; 10.93%). Based on Cramer's V coefficients, the association between the presence of anxiety or depression and the psychiatric disease group is comparatively the strongest, i.e. 0.58, which indicates a strong association.

#### 3.5 Patient satisfaction with family physicians

Patients' satisfaction with their FP proved to be not statistically significant when associated with the observed quality variables (Table 5). Inspection of the column percentages and standard residuals in this crosstab shows that the percentage of satisfied respondents without problems in everyday activities was lower, at 61.0%, than the overall average (66.7%), whereas that for satisfied respondents (69.3%) was above average. In addition, corresponding Cramer's V coefficients showed that all relationships were negligible.

**Table 5**. HRQoL and patient/Roma satisfaction with family physicians.

HRQoL	P	atient satisfaction with FI	Ps
	UNSATISFIED	SATISFIED	TOTAL
MOBILITY			
Without problems	113 (63.84%)	243 (62.63%)	356 (63.01%)
Moderate problems	61 (34.46%)	142 (36.60%)	203 (35.93%)
Severe problems	3 (1.69%)	3 (0.77%)	6 (1.06%)
·	177 (100%)	388 (100%)	565 (100%)
Chi-square=1.15; df=2; p=0.56 Cramer's V=0.05			
CARE OF SELF			
Without problems	156 (88.14%)	343 (88.40%)	499 (88.32%)
Moderate problems	17 (9.60)	42 (10.82%)	59 (10.44%)
Severe problems	4 (2.26%)	3 (0.77%)	7 (1.24%)
N	177 (100%)	388 (100%)	565 (100%)
Chi-square=2.34; df=2; p=0.31 Cramer's V=0.06	, ,	, ,	,
PRESENCE OF PAIN			
Without problems	62 (35.03%)	140 (36.08)	202 (35.75%)
Moderate problems	100 (56.50)	214 (55.15)	314 (55.58%)
Severe problems	15 (8.47)	34 (8.76)	49 (8.67%)
N .	177 (100%)	388 (100%)	565 (100%)
Chi-square=0.09; df=2; p=0.96 Cramer's V=0.09	, ,	, ,	, ,
DIFFICULTY IN EVERYDAY ACTIVITIES			
Without problems	108 (61.02%)	269 (69.33%)	377 (66.73%)
Moderate problems	57 (32.20%)	106 (27.32%)	163 (28.85%)
Severe problems	12 (6.78%)	13 (3.35%)	25 (4.42)
N .	177 (100%)	388 (100%)	565 (100%)
Chi-square=5.49; df=2; p=0.06 Cramer's V=0.10	,	,	,
PRESENCE OF ANXIETY AND/OR DEPRESSION			
Without problems	91 (51.41%)	196 (50.52%)	287 (50.80%)
Moderate problems	68 (38.42%)	162 (41.75%)	230 (40.71%)
Severe problems	18 (10.17%)	30 (7.73%)	48 (8.50%)
N	177 (100%)	388 (100%)	565 (100%)
Chi-square=1.20; df=2; p=0.55 Cramer's V=0.05	(,	()	222 (124/0)

#### 4 DISCUSSION

In our sample, we included almost 20% of the Roma in Prekmurje. This is a large proportion, and most Roma studies do not include so many participants; this can be seen as one of the strengths of our study. The results showed that there were statistically significant differences between people with and without chronic diseases in terms of HRQoL for each chronic disease group. The analysis included only the chronic disease groups in which 200 or more Roma reported they have the disease, so the respiratory disease group, with only 126 subjects, was not included and we would like to analyse it separately. In the analysis, we only used data on self-reported diseases, and the community nurses gave exact descriptions of the chronic diseases where necessary, but this was not a problem for the interviewees. Some other studies also led to the conclusion that Roma with chronic diseases experience a significant reduction in HRQoL (21, 33-35). Studies that assessed HRQoL in a population with chronic diseases are sometimes conflicting; for example, in the Makkes study, they did not find any associations between HRQoL and cardio-metabolic risk factors (36), and another study researched a multi-ethnic sample of breast cancer survivors where the women reported levels of HRQoL comparable to established norms (37).

In our study, however, we were able to find associations between lower HRQoL and the presence of chronic disease.

Of the chronic diseases studied, we particularly looked at symptoms related to the lowest HRQoL. The presence of pain and problems with mobility in the group with musculoskeletal diseases were two negative factors that had an important role in terms of the patients' quality of life. In the group with mental problems and the lowest HRQoL, the presence of anxiety and depression had the most important negative association on quality of life. That mental status has a large impact on health was also pointed out in Pranesh's study (38). Some other studies reported the important impact of psychological symptoms, life stress and religiosity/spiritualism on HRQoL, but in our study we did not measure those components (39-42). One interesting finding in the study, with an analysis like that, was in

the group with cardiovascular diseases, where problems with pain were significant but not, as expected, problems with anxiety and mobility. Perhaps this can be attributed to the perception of health by the Roma. Most qualitative studies in Roma populations show that for Roma people, health is a life without pain (43-45), so problems with health are usually associated with pain and unhappiness, which may explain our results (43, 46). On the other hand, a small study from the general population in Slovenia also pointed out that the presence of pain, mobility problems and anxiety have a negative impact on HRQoL (47).

If we use our sample as representative of Prekmurje Roma, almost all (96.4%) are registered with an FP. Patients with chronic diseases are frequent attendees at FP clinics and are satisfied with them (11, 48, 49). They have increased anxiety and depression with lower perceived HRQoL (49). In our sample, we did not find any statistically significant associations between satisfaction with FP and HRQoL.

The questions about satisfaction with the FP included 6 items that were related to communication, explanation, time for and interest in the patients' problems. Typically there are communication problems between Roma and medical staff, which can form a barrier towards good relationships (43-45, 50-52). That could also be an explanation for the negligible relationship between satisfaction with FP and HRQoL in our study.

#### 4.1 Limitations of the study

The questionnaire was not translated into the Romani language, and community nurses who usually work in Roma settlements helped in data collection, so we cannot exclude the fact that the Roma want to please and the data could be biased, especially regarding satisfaction. Because of the small sample, only three groups for chronic disease were formed, so we possibly lost some comparisons with other diseases that were not selected. The heterogeneity of CVD with risk factors for them and the lack of the multimorbidity aspect are also limitations of our study. We also did not measure the impact of socioeconomic variables on HRQoL in the chosen instrument. Further studies are needed to develop this topic.

#### **5 CONCLUSION**

The presence of pain, anxiety and depression were negatively associated with HRQoL. The lowest HRQoL was found in the group with mental health problems and the presence of anxiety and depression symptoms. This is an important finding that suggests that FPs should pay more attention to the subgroup of the Roma population with mental health problems. Intervention programs that address this will be necessary in future to increase the HRQoL of this group.

#### CONFLICT OF INTEREST

The authors declare that no conflict of interest exists.

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#### ETHICAL APPROVAL

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