Health-Related Quality of Life and Chronic Disease Status of Roman People in Zonguldak

Zonguldak'ta Yaşayan Romanların Sağlıkla İlişkili Yaşam Kalitesi ve Kronik Hastalık Durumu

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ABSTRACT Objective: Roman People are faced with health problems such as chronic disease, disabilities and limitations with work and daily activities, compared to general population. This study was planned to examine chronic disease and sociodemographic characteristics affecting their health-related quality of life (HQOL) status of Roman People. **Materials and Methods:** Cross-sectional typed this study was carried out with 317 Roman People who selected randomly in Karaelmas Family Health Center in Zonguldak city between February 1-April 30, 2015. There are many Roman people living in the Karaelmas region. They were 18 years old and above, who had no communication problems and who were willing to participate were included in the study. Data were collected with a questionnaire which was prepared by the researchers and including 11 items questioning sociodemographics and the presence of any disease, and SF-36 health-related quality of life (SF-36 HQOL questionnaire. Data were evaluated by SPSS 20.0 program. Means, standard deviations, percentages, Mann Whitney U and Kruskal Wallis tests, Spearman correlation tests were used for the evaluation of data. **Results and Conclusion:** The most common chronic disease in Roman People is hypertension (23.9%). Besides, there was an additional disease (comorbidity) in 19.4% of the Roman People. It was found that HQOL was lower in the ones having a chronic disease and sociodemographic characteristics as age, education, and employment status significantly affected health-related quality of life. Quality of scores of the individuals whose education level was high and who were employed were found to be significantly high. A negative and significantly high relationship was found between age and HQOL. The lowest score was from vitality and the highest score was from social function domains. Keeping chronic disease status in the forefront but not ruling out income and educational status might be recommended for the evaluation of HQOL and it is suggested to organize trainings about the factors affecting of HQOL of the Roman People.
Key Words: Roman people, health-related quality of life, chronic disease,

ÖZ Amaç: Romanlar genel popülasyona kıyasla kronik hastalık gibi sağlık sorunları, engellilik, iş ve günlük faaliyetlerle ilgili sınırlamalar ile karşı karşıyadırlar. Bu çalışma Romanların kronik hastalık durumlarını ve sağlıkla ilişkili yaşam kalitesini (HQOL) etkileyen sosyodemografik özelliklerini incelemek amacıyla planlanmıştır.**Gereç ve Yöntem:** Kesitsel tipteki bu çalışma 1 Şubat-30 Nisan 2015 tarihleri arasında Zonguldak ilinde Karaelmas Aile Sağlığı Merkezi'ne başvuran 317 Roman üzerinde yapılmıştır. 18 yaş ve üstü olan, iletişim engeli olmayan ve çalışmaya katılmaya istekli Romanlar araştırmaya dahil edilmiştir. Veriler araştırmacılar tarafından hazırlanan, sosyodemografik özellikleri ve hastalık varlığını sorgulayan 11 maddeden oluşan anket formu ve SF-36 yaşam kalitesi ölçeği ile toplanmıştır. **Bulgular ve Sonuç**: Romanlarda en yaygın görülen kronik hastalık hipertansiyondur. Yanı sıra % 19,4'ünde eşlik eden kronik bir hastalık vardır. Kronik hastalığı olanların yaşam kalitesinin daha düşük olduğu, sosyodemografik özelliklerinden yaş, eğitim, ekonomik ve çalışma durumunun yaşam kalitesini etkilediği bulunmuştur($p<0.05$).Yaşam kalitesinin en düşük puanı canlılık, en yüksek puanı sosyal fonksiyon alanındandır. Yaşam kalitesi değerlendirilmesinde kronik hastalık durumunun ön planda tutulması, ancak sosyodemografik özelliklerden gelir ve öğrenim durumunun da göz ardı edilmemesi, Romanların yaşam kalitesini etkileyen faktörler hakkında düzenli eğitimler yapılması önerilebilir.
Anahtar Kelimeler: Romanlar, Sağlıkla İlişkili Yaşam Kalitesi, Kronik Hastalık

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Introductıon

Roman are one of the social groups that is exposed to inequalities derived from social structure of the society as well as status system(1). According to International Roma Studies Network (2005); it is estimated that the number of all Roman People in Turkey is around 1% (2). It can be said that the number of Roman People is less than 5% of the population in Zonguldak city (3). Roman People living in Turkey have a lower educational and employment level and worse accommodation conditions compared to other ethnic groups and they are exposed to more ethnic discrimination(2). Health status of Roman are also worse than the other ethnic groups. The causes of this difference are mostly negative accommodation conditions, their limitations for healthcare services and educational opportunities and discrimination (4-6). Compared to general population, they are faced with health problems such as chronic disease, disabilities and limitations with work and daily activities (7). The most common health problems experienced are tuberculosis, skin diseases, hepatitis, anxiety, depression, diabetes, angina, respiratory diseases and arthritis (5,6,8). It was previously reported that health-related risk factors were higher, average lifetime was decreased and morbidity of chronic disease was increased in Roman People compared to non-Roman People (4). Health-related quality of life of individuals who have diagnosed with a chronic disease can be impaired as a result of many symptoms and complications due to the disease; and increasing HQOL of the individuals is one of the fundamental goals of the treatment of chronic disease (9). Quality of life is basically a type of pleasure that affects personal satisfaction in adaptation of the individual to the living conditions. HQOL is a concept that was developed to describe direct or indirect subjective experiences of an individual such as health, disease, disability, handicap and efficacy of the treatment have described the concept of HQOL with interaction model between biological functions of the individuals, disease symptoms, functional status and general health perception, in which personal characteristics of the individuals and their surrounding are considered (10,11). In the evaluation of HQOL measurements in the field of healthcare, determination and control of psychosocial problems in patient care, population studies about health problems, measurement outcomes about healthcare services and health research, clinical studies and cost benefit analysis studies are used (12). For improving HQOL in Roman people, not only low socioeconomic status, but also other factors about their own ethnic origin such as cultural structure and living conditions should be among the goals of care (4). The studies on this subject have shown that the awareness of healthcare professionals about care requirements of ethnic patients would increase as they got cultural approach education, and an open and flexible communication would develop between both groups (6). Although there are many studies about belief and health practice that were performed on various ethnic groups, the studies evaluating chronic diseases and HQOL among Roman People are limited (4,13,14). Therefore; this study, that we planned by addressing this lack, was performed to examine chronic disease status of Roman People and their sociodemographic characteristics affecting HQOL.

Materials and Methods

Design, Setting and Sample

Cross-sectional study was carried out with 317 Roman People who selected randomly in Karaelmas Family Health Center which is applied for generally by Roman People in a rural area of the Zonguldak city between February 1-April 30, 2015. There are many Roman people living in the Karaelmas region. People choosen from Roman People were 18 years old and above, had no communication problems and were willing to participate in the study.

Data Collection

Data were collected by a questionnaire that was prepared by the researchers (4,13,14) and including 11 items questioning sociodemographics (age, sex, education, marital and employment status) and presence of chronic disease, and SF-36 health-related

quality of life questionnaire which was developed by Ware (15) and had a validity and reliability study by Kocyigit et al (16). SF-36 which was generated with 36 statements is like a multi-headed scale with 2 main scales including physical and mental health; and 8 subscales including physical function, social function, physical role, emotional role, mental health, vitality, pain and general health perception. The quality of life scores increases as the score increases for all subscales. Scale scores of health-associated living quarters in the scale have values varying between 0 and 100 from the lowest to the highest score. The quality of life scores increases as the score increases. SF-36 was scored such that health-associated health-related quality of life will increase as the score of each health area increases (15).

Data Analysis

Data were evaluated by SPSS 20.0 program. The Kolmogorov Smirnov test, in which the data were not normally distributed, was examined. Means, standard deviations, percentages, Mann Whitney U and Kruskal Wallis tests, Spearman correlation tests were used for the evaluation of data. Difference of data were accepted as a significance of $p < 0.05$. Cronbach alpha was found 0.86 in this study for SF-36 Scale.

Ethical Considerations

Prior to the study, written permission was taken from the Bulent Ecevit University Ethical Board. Each patient was informed about the study and written informed consent was taken from the patients. We ran the study according to the Helsinki Declaration (World Medical Association Declaration of Helsinki Ethical Principles For Medical Research Involving Human Subjects, 2015 (17).

Results

Mean age of the Roman People in the study was 46.8±17.41 years (range: 18-86 years); and 64.7% of them were women. 94.4% of the individuals have lived in city during most of their lives and 84.3% were married. 43% of them have graduated from elementary school, 55.3% were housewives, and 77% were not employed. 32% of the individuals were smoking and 8% the Roman People were drinking alcohol. 67% of the Roman People included in the study were diagnosed with a chronic disease. Mean duration of disease was 4,52±6,25 years. Distribution of chronic diseases of Roman People were given in Table 1. They were hypertension (23.9%), diabetes mellitus (16.4%), respiratory tract diseases (10%) and cardiac diseases (9,5%). Besides, there was an additional disease (comorbidity) in 19.4% of the Roman people.

Table 1. Distribution of Chronic Diseases of the Roman People(n=317)

Chronic disease	n (%)
Hypertension	48 (23,9)
Diabetes Mellitus (DM)	33 (16,4)
Respiratory tract diseases (COPD, Asthma, tuberculosis)	20 (10,0)
Cardiac diseases	19 (9,5)
Other*	81(40,2)
No comorbidity	151 (75,1)
1 comorbidity	39 (19,4)
2 comorbidities	11 (5,5)

* Cancers, Goitr, Prostate Hypertrophy, Arthritis, Anemia, Depression, Herniated Disc, Rheumatismal Diseases, Thyroid Disease

The scores SF-36 health-related quality of life subscales of Roman People were given in Table 2. The Roman People who had a chronic disease from all subscales scores ($p \leq 0.0001$), physical health ($p \leq 0.0001$), mental health ($p \leq 0.05$), and total SF36 scores ($p \leq 0.0001$), were significantly lower compared to the ones who had not a chronic disease.

Distribution of SF-36 health-related quality of life scores of Roman People based on their sociodemographic characteristics were given in Table 3. Distribution of SF-36 health-related quality of life scores of Roman People based on their sociodemographic characteristics were given in Table 3.

Table 2. Mean Scores of Roman People had or hadn't a Chronic Disease from SF-36 HQOL (N=317)

SF-36 Subscales (u)	General mean ±SD	Had a Chronic Disease	Had not a Chronic disease	z	p
Physical Function	79,1±26,92	71,2±28,90	94,9±11,10**	8,585	0,000
Physical Role	62,3±44,86	50,2±45,55	86,8±31,61**	6,926	0,000
Pain	67,3±23,24	61,7±24,33	78,7±15,62**	6,129	0,000
General Health Perception	50,5±17,86	45,3±16,45	61,3±15,75**	7,428	0,000
Vitality	45,0±21,12	41,0±19,02	53,1±22,86**	4,302	0,000
Social Function	80,8±19,93	76,0±21,02	90,6±12,91**	6,169	0,000
Emotional Role	69,3±40,98	62,0±43,97	84,2±29,09**	4,059	0,000
Mental Health	56,0±15,86	54,8±15,88	58,6±15,58*	1,984	0,047
Physical Health	64,8±22,01	57,1±21,81	80,4±11,76**	9,460	0.000
Mental Health	62,8±18,86	58,5±19,30	71,7±14,40**	5,620	0,000
Total SF36	63,8±17,93	57,8±17,63	76,1±10,96**	8,749	0,000

* p≤0.05, ** p≤0.0001 (physical function, social function, physical role, emotional role, mental health, vitality, general health perception, pain) 2 main scales physical and mental health

Table 3. Health-Related Quality of Life Scores of the Roman People based on their Sociodemographic Characteristics (N=317)

Sociodemographic Characteristics		(n %)	Physical Health Mean±SD	Mental Health Mean±SD	SF 36 Total Mean±SD
Sex	Female	205 (64.7)	64,9±22,00	68,0±20,17	62,8±18,28
	Male	112 (35.3)	64,6±22,10	63,5±18,63	65,7±17,1
z P			0,094 0,925	0,657 0,098	-1,328 0,185
Educational Status**	Illiterate	73 (23.0)	58,6±25,67	62,6±22,06	60,6±21,40
	Literate	39 (12.3)	62,5±25,52	54,8±17,19	58,7±20,06
	Elementary school	136 (43.0)	62,5±25,52	64,5±16,93	64,7±14,64
	High school	59 (18.7)	71,4±19,59	62,2±19,26	66,8±18,08
	Undergraduate and above*	10 (3.0)	80,4±15,06	76,6±11,83	78,5±9,87
Kw-X^2 p			16,624 **0,002**	14,706 **0,005**	12,094 **0,017**
Marital status	Married	267 (84.3)	64,3±21,69	62,4±18,57	63,3±17,60
	Single	50 (15.7)	67,6±23,68	65,0±20,46	66,3±19,62
z p			1,591 0,112	0,970 0,332	1,321 0,186
Employment status**	Employed	73 (23.7)	73,9±18,17	68,4±16,59	71,1±15,40
	Unemployed	244 (66.3)	62,1±22,37	61,2±19,22	61,6±18,08
z p			-4,139 **0,000**	-2,686 **0,007**	-4,075 **0,000**

The employed individuals had higher Quality of scores (Physical, mental and total) than unemployed individuals. Individuals who undergraduate and above had higher quality of scores (Physical, mental and SF-36 total) than people with other education levels. Health-related quality of life scores of the Roman People were not different according to sex and marital status. We were found significantly higher of a negative and significantly high relationship was found between age and HQOL. Significantly high negative correlations were found between age and physical health (r=-0,587), mental health (r=-0,307) and SF 36 Total score (r=-0,522).

Discussion

Quality of life is basically a type of satisfaction affecting personal satisfaction in adaptation of the individual to the living conditions. It was described as the level of saturation that an individual feels about his/her own life or surrounding (18). Roman People are sensitive groups which live under unhealthy conditions within the societies they live with, whose income levels are low and who present with chronic diseases. Despite this, there are limited number of studies evaluating chronic disease status and life quality of Roman People (4,13,14). In this study, it was found that sociodemographic characteristics of Roman People such as age, education, and employment status and the presence of chronic disease affected HQOLThe average age of the Roman Group studied in this study was 46 and approximately two-thirds were females. In this study, it was probable that the youth and male populations were low. Possible reasons for this are migration to large cities to work. A high degree of correlation was observed between the increase in age and the decrease in SF-36 health-related quality of life subscale scores among Roman people. As in this study, Pappa et al, a significant decrease was reported in the SF-36 health-related quality of life scores in correlation with age (13). Also in the study by Vaish et al also showed that age was a significant determinant for health-related quality of life among Indian people who were presented with a chronic headache (19). In this study, SF-36 scale scores of the Roman People who were employed were found to be higher than the ones who were unemployed. These findings shows that being employed increases HQOL of the Roman people. In this study, no significant difference was found betwen marital status of the Roman People and any of the scores from health-related quality of life. In the study by Pappa et al evaluating HQOL of Roman People in Greece, mean scores from physical function, physical role and emotional role were found to be lower in singles and divorces; and they found other subscale scores similar to this study. The differences in quality of life according to marital status may be due to regional differences Pappa's and our study, as well as the evaluation of single and divorced people in this study (13). In our study, there is not a significant difference between men and women in terms of health-related quality of life in Roman people. In the study by Rollero et al that was performed Roman society in Italia and in the study by Pappa which was performed on Roman population in Greece, All HQOL scales were found decrease in women compared to men except social relationships scores (13,20). It also may be these differences might be regional differences.In this study, presence of a chronic disease in two third of adult Roman People is remarkable. While it is expected to see infectious diseases more in this group due to poor hygienic conditions, presence of such a high level of chronic diseases suggests that there is a need for health promotion for these groups such as giving up smoking, healthy diet and increasing physical activity. In the study by Koyun and Çiçeklioğlu (2011), 87.9% of the Roman People have indicated that they have not taken any health care service except disease state and 7.4% have not taken any healthcare service; and this supports above-mentioned view (21). This subject needs to be given importance since there was hypertension in 23.9%, diabetes mellitus in 16.4%, respiratory diseases in 10% and cardiac disease in 9.5% of Roman People included in our sample group. In the study of Törö et al. (2017) comparing the general and Roman population in Hungary; cancer and pain fequency lower than the general population, but other chronic diseases frequency was higher than general populations. There was no difference between general and roman populations with regard to diabetes mellitus and the frequencies were similar to our study. Hypertension is the most common chronic disease problem in the Roma population similarly to our

findings in Törö et al. Depression frequency was the second most important problem in their study. This value was considerably higher than the values in our study. This can also be regarded as a regional difference (14). It was reported the extreme health inequalities experienced by romans and the need for specific action to reduce them and improve access to health care, nurses are identified as needing to play a key part as role models in challenging inequality and exclusion. The most significant factor determining health-related quality of life in Roman people was the presence of at least one chronic disease. All of SF-36 subscale scores of Roman People had a chronic disease were found to be significantly lower compared to the ones hadn't a chronic disease. Similarly, in the study by Altiparmak and Eser which was performed on housewives in Manisa city, presence of a chronic disease was found to decrease HQOL significantly (22). Moreover, Pappa et al have declareted that all subscale scores of HQOL have decreased in the presence of a chronic disease in of Roman People in Greece (13). While mean score of physical health from HQOL among Roman People in our study (63.8) was similar to the mean score of physical health of Roma population in Greece in the study by Pappa et al (67.6); mean score of mental health in this study (62.8) was found to be significantly higher than the mean score of mental health found in the study by Pappa et al (47.09) (13). The reason of this may be derived from the fact that living conditions and standards may be different among Roma populations in different countries. Skodova et al also detected that HQOL scores of coronary artery patients of Roman People were similarly lower than non-Roma patients (4).

Conclusion

This study is one of the rare studies evaluating chronic disease states and HQOL of the Roman population. Health quality of life is higher in Romans that do not have any chronic disease, are younger, have undergraduate or higher education, and has a job. In this study, Roman citizens who were diagnosed with chronic illness were found to be adversely affected by the HQOL level. Therefore, interventions should be planned to reduce the risk factors of chronic diseases in this vulnerable group. In these groups, appropriate management of chronic diseases should be provided early diagnosis and periodic examination and health quality of life should be increased.

Conflicts of Interest: None.

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