

## ASSESSMENT OF QUALITY CARE OF CHRONIC ILLNESS PATIENTS LIVING IN ROMA COLONIES AND IN THE GENERAL POPULATION: A COMPARATIVE STUDY

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### ABSTRACT

Health status of the Hungarian population is rather unfavourable compared to the developed countries of the European Union. In Hungary, similarly to other developed countries, the biggest challenge is the care of chronic patients. The purpose of the study was to assess the quality of medical care of patients with chronic diseases among the general population of Szabolcs-Szatmár-Bereg County and the population living in Roma colonies, as well as the problems of the doctor-patient relationship, emphasizing the advantages and deficiencies related to the medical care. The survey used a self-completion questionnaire developed in the United States (Patient Assessment of Chronic Illness Care - PACIC) for the assessment of the quality of care among the general population suffering from chronic diseases (n=721) in 2013 and among the population living in Roma colonies (n=477) in 2016. The study sample was selected randomly, from the official records of the general practitioners' praxes with operating licence in the settlements of Szabolcs-Szatmár-Bereg County and from the records of the identified colonies. As regards the frequency of the occurrence of chronic diseases, the prevalence of hypertension was prominent in both examinations (among people living in colonies 48.0% versus general population 37.9%;  $p < 0.001$ ). The prevalence of cancers was significantly higher among the general population compared to the respondents living in Roma colonies (17.7% versus 4.4%;  $p < 0.001$ ). 44.4% of the general population, 46.5% of the respondents living in colonies suffered from one chronic disease. Respondents from the general population were more satisfied with their care, the total scores of the answers were higher in each case as compared to the population living in Roma colonies. Morbidity indices of the Hungarian population, especially of the population living in Roma colonies, showed rather unfavourable picture. At the level of primary care in the treatment

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Received: 6<sup>th</sup> April 2017

Accepted: 2<sup>nd</sup> May 2017

of patients with chronic diseases it is necessary to improve the quality of care especially among people living in Roma colonies, which could result in significant improvement of quality of life.

**KEY WORDS:** chronic care model, chronic diseases, primary care, quality assessment of chronic illness care, Roma colonies

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## INTRODUCTION

According to the data of WHO cardiovascular diseases, diabetes, cancers, chronic respiratory diseases and mental diseases are responsible altogether for 86% of deaths. Within this cardiovascular diseases, with 30% of deaths, are the leading cause of death all over the world and cancers, with 13%, are the second most frequent cause of death (Busse et al., 2010; Molnár and Barna, 2012; GYEMSZI 2013; World Health Statistics 2016).

Although ischaemic heart disease and cancer mortality has recently decreased in the countries of the European Union, in Hungary the number of deaths per 100,000 inhabitants is still prominently high. Based on the data of Eurostat (2013), in 2013 the standardized mortality rate of lung cancer (89 deaths per 100,000 inhabitants) and colon cancer (56 deaths per 100,000 inhabitants) was the highest in Hungary among the EU member states.

The General Practitioners' Programme for Morbidity Data Collection (HMAP) Health Observatory work team of North-Eastern Hungary examined the frequency of the development of hypertension, stroke, diabetes and chronic liver diseases in three counties (Hajdú-Bihar County; Szabolcs-Szatmár-Bereg County and Heves County). In case of the circulatory diseases the greatest increase could be observed in Szabolcs-Szatmár-Bereg County. In the examined period (1998 – 2007) hypertension doubled among young people living in Szabolcs-Szatmár-Bereg County and among the old age-group it was prominently high internationally as well. The increase of the frequency of diabetes was also prominent in Szabolcs-Szatmár-Bereg County, as compared to the before-mentioned two counties (Széles, 2007).

Health condition of the population living in Roma colonies (76% declared themselves to be of Roma ethnicity) significantly differs from the health condition of the general population (Environmental Health Hazards of Ethnic Minorities Living in Colonies). The previous studies proved that their lifestyle was more unfavourable compared to the general population (e.g. smoking habit) and low frequency of the use of medical services contributed to the increase of the number of people suffering from chronic diseases (Ungváry et al., 2016). The mental health problem was also found high in the unemployment group of Roma people leading to physical complaints (Ungváry et al., 2015a; 2015b). The appropriate care of people suffering from chronic diseases means bigger and bigger challenge to health care.

The purpose of this survey was to assess the quality of medical care of patients suffering from chronic diseases and living in Roma colonies and to compare it to the data of the general population, by the help of the Patient Assessment of Chronic Illness Care - (PACIC) questionnaire.

When examining the quality of care, our aim was to know the patients' opinion about their health care, to assess the quality of patient briefing and the patients' participation in the course of their care.

## METHODS

### Chronic Care Model

The so-called Chronic Care Model (*Figure 1.*) has been developed in the United States in order to improve the care of the patients with chronic diseases. The model has already been applied for a number of chronic diseases, health care systems and target populations. Its most important elements are community approach, support of self-management, coordination of care, development and application of protocols and guidelines. In the course of the quality care the patient and the health care system are in close relationship. By appropriate support 70-80% of the patients are able to actively participate and co-operate in the prevention of complications (Rékassy et al., 2005; Dózsa, 2009).

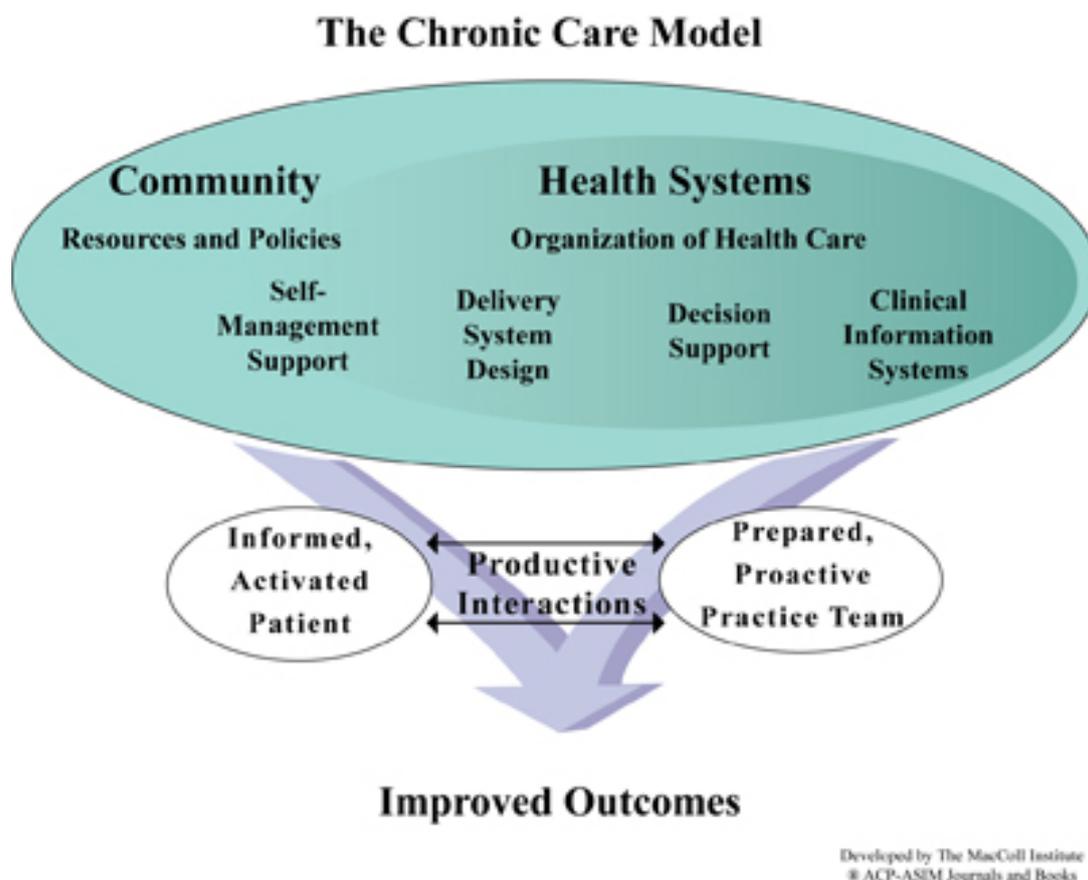


Figure 1. The Chronic Care Model (CCM 2009)

## PACIC questionnaire

In order to assess the quality of care the PACIC questionnaire was used, which intended to survey how patients receiving chronic care see their participation, collaboration in their own care. The brief version of the PACIC questionnaire contains 20 questions about the quality of care. The 20 questions cover 5 topics: patient activation; delivery system design /decision support; goal setting; problem-solving/contextual counselling; follow-up/coordination). In case of each question the chosen patients grade the quality of the care they received in the last 6 months within the primary care on a scale from 1 (never) up to 5 (always). Evaluation is made by averaging the scores given to the various elements, hereinafter referred to as the average of the PACIC scores (The Chronic Care Model, 2017).

The original questionnaire was completed with questions about demographical data. In order to examine the internal consistence of the questions within the 5 topics of the 20 questions Cronbach's alpha test was used. Grouping of the questionnaire's questions was found to be appropriate, the topics consistence among the questions can be seen in *Table I*.

**TABLE I.**

### Grouping of the questions of the PACIC questionnaire as per topics

Topics	Cronbach $\alpha$
Patient activation	0.875
Delivery system design/ Decision support	0.635
Goal setting	0.787
Problem-solving/ Contextual counselling	0.771
Follow-up/ Coordination	0.765

The Hungarian adaptation of the self-completing PACIC questionnaire used in the survey was made in 2013, based on the guidelines of the WHO (WHO Process of translation and adaptation of instruments). The questionnaires were forwarded to the chronic patients by the help of the community nurses working with the general practitioners (GP). The nurses were preliminarily presented with the research plan and the survey's aims. Anonymity was emphasized so that

the personage of the GP would not influence the response. The patients put the completed questionnaires into a closed collecting box placed in the waiting-room.

## **Sampling**

### *Survey in the general population*

As the first step in the two-step sampling, the GPs' praxes (n=15) were involved by random selection based on the official register of the GPs' praxes with operating licence in Szabolcs-Szatmár-Bereg County then the recruited persons were selected from the database of the patients suffering from chronic diseases arranged by birth order (n=800). The first survey was performed in the period from February 2013 until October 2013.

### *Survey among people living in colonies*

The survey was repeated in the period from March until May 2016 among the inhabitants living in Roma colonies of the same county and suffering from chronic diseases. In case of people in Roma colonies 5 from among the previously examined colonies got into the sample at random. Kósa K. and her colleagues completed the survey of the settlements/colonies in 2001 and later Kósa Zs. and his colleagues made the health assessment of the population living in Roma colonies. According to the survey 76% of the population living in Roma colonies declared themselves Roma (Kósa K. et al., 2002; Kósa Zs. et al., 2007). In this paper the population living in Roma colonies is mentioned as Roma.

## **Statistical analysis**

SPSS 19.0 statistical programme was used for data recording and analysis. For the presentation of the results frequency indices and their 95% confidence intervals (95% CI) were used and association analyses (chi-square test, two-sample t-test, Mann-Whitney test) were performed.

## **RESULTS**

From the 800 questionnaires distributed among the general population 721 ones were returned to us all of which could be evaluated. We compared the results with the results of the processed questionnaires of the 477 respondents living in Roma colonies that got into the sample.

When analysing the demographical data, we did not find any significant difference between the two examined groups as regards age, gender and marital status. In the 2013 survey 63% of the respondents were over 40 years, 57% of them were women. 52% of the respondents lived in a village. As regards their marital status, 37% of them were married, 58% of them lived alone. 62.8% of the Roma population completing the questionnaire were over 40 years, 63.7% of them were women. As regards education, 83% of the Roma respondents had education lower than primary school or they just completed primary school. In the general population the rate

of people with education lower than primary school or with primary school was 37.6%, while 46.2% of them had secondary education and 16.2% had even higher level of education. (Table II.)

TABLE II.

### Demographical data of the patients involved in the survey

Demographical data	General population N=721	People living in Roma colonies N=477
average age (year)	46.3	47.9
<b>Gender</b>		
female	57.1 %	63.7 %
male	42.9 %	36.3 %
<b>Marital status</b>		
married	37.4 %	42.1 %
widow	25.0 %	15.1 %
single	19.0 %	14.9 %
divorced	13.3 %	6.9 %
other	5.3 %	21.0 %
<b>Education</b>		
< primary school	9.2 %	41.5 %
primary school	28.4 %	41.5 %
secondary school/ secondary grammar school	46.2 %	14.0 %
college/university	16.2 %	2.9 %

### Frequency of chronic diseases

Respondents could mark the diseases they suffered from among the chronic diseases indicated in Table III. In the survey of 2013 we received the highest value of frequency in case of high blood-pressure and chronic pain but prevalence of diabetes and cancer was also significant. Among the Roma respondents the prevalence of hypertension, chronic pain and depression was prominent. With the exception of diabetes significant difference could be detected between the two groups. According to our survey prevalence of cancers was significantly lower among the Roma population (4.4%) as compared to the general population (17.8%). 26.8% of the Roma patients completing the questionnaire and 37.3% of the general population lived with

chronic pain. Prevalence of depression was significantly higher among the Roma respondents as compared to the general population (28.7% vs. 16.1%;  $p < 0.001$ ). The number of asthmatic patients was nearly identical in both groups.

TABLE III.

**Frequency of the occurrence of chronic diseases in the general population and among people living in Roma colonies**

Chronic diseases	General population (95% CI)	People living in Roma colonies (95% CI)	p-value
Diabetes	17.29% (95% CI:14.64 – 20.29)	15.9% (95% CI:12.82 – 19.6)	0.052
Cancers*	17.70% (95% CI:15.09 – 20.65)	4.4% (95% CI:2.81 – 6.76)	< 0.001
Hypertension*	37.90% (95% CI:34.44 – 41.49)	48% (95% CI:43.46 – 52.6)	< 0.001
Pain*	37.21% (95% CI:33.76 – 40.79)	26.8% (95% CI:22.95 – 31.09)	< 0.001
Arthritis*	13.14% (95% CI:10.87 – 15.8)	21.2% (95% CI:17.64 – 25.17)	< 0.001
Depression*	16.04% (95% CI:13.55 – 18.89)	28.7% (95% CI:24.74 – 33.05)	< 0.001
Asthma	11.48% (95% CI:9.36 – 14.01)	13.8% (95% CI:10.93 – 17.34)	0.035

\*Chi-square test

44.4% of the general population lived with one and 39.9% lived with two chronic diseases. Close to 30% of the Roma respondents suffered from at least three chronic diseases (*Figure 2*).

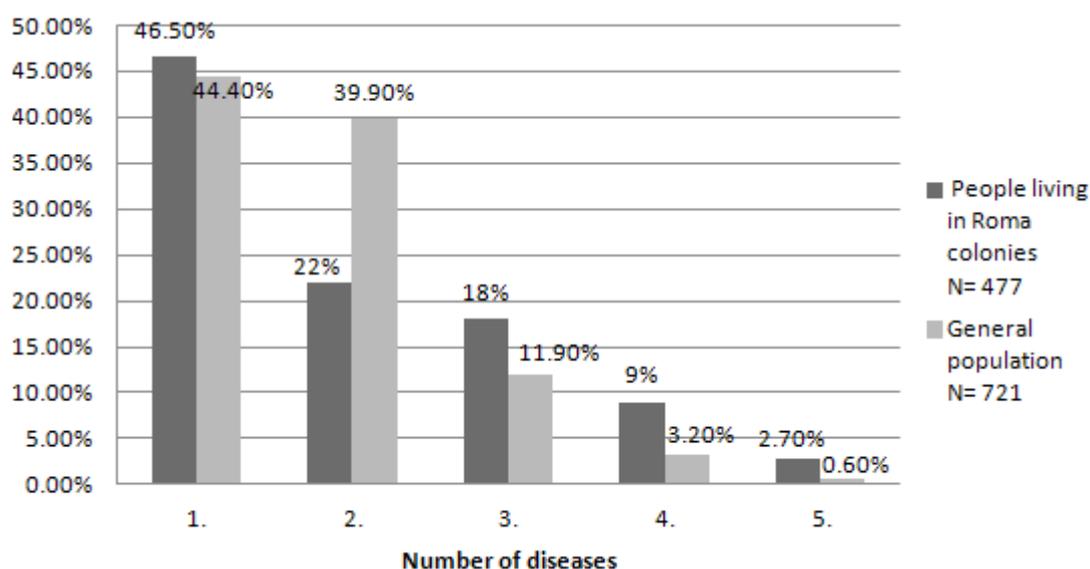


Figure 2. Number of chronic diseases among people living in Roma colonies and in the general population

## Quality of care of chronic patients

Based on the results of the responses about the quality of care in the category of patient activation significant difference ( $p < 0.05$ ) was found in almost every question between the responses of the general population and the Roma patients. The category of patient activation intends to examine how patients participate in their medical care. The higher average scores of the answers to these questions refer to higher self-activity.

Based on the responses of the general population 58.8% were informed about the possible treatments almost in every case by the physician. 45.5% of the patients chose the appropriate treatment plan in close co-operation with the physician, taking the problems occurring during the care into account. 2.4% of the respondents (3.4% of the Roma) were never informed about the possible treatments. Less than half, 49.5% of the Roma respondents stated that they spoke about the choices of the appropriate treatment with their GP very often, 34.8% of them were asked about their opinion almost in every case when making the treatment plan.

62.9% of the general population and 53.8% of the Roma respondents declared that they had been asked about their possible problems related to medication.

21.8% of the Romany respondents and 11.5% of the general population never received any written document for the maintenance or improvement of their health but 56.4% of the Roma and 64.8% of the general population were informed about how their lifestyle could affect their health and condition almost in every case. 36.7% of the Roma and 30.8% of the general population received similar information only rarely.

56.6% of the general population and 41.5% of the Roma population reported that the GP or the nurse helped to set special goals in order to improve their condition but only nearly 30% received it in the form of a written document in either group. In case of the general population more than half of the respondents (51.5%) and in case of the Roma population 42.3% never received the treatment plan in a written form.

52.6% of the general population while barely 37% of the Roma respondents were encouraged to go to specific group courses, clubs or classes where they could learn more about their illness, or they could get assistance suitable for the improvement of their condition and for the maintenance of the quality of life. Such a possibility was almost never recommended to 37.6% of the Roma respondents and 26.5% of the participants from the general population.

Between the two groups significant difference ( $p < 0.001$ ) was found in the responses to the questions how the GP prepared the patients for the possible decay of their condition and what help they received in order to adapt themselves to this. 65.2% of the general population answered that they had been prepared for the solution of the problems related to their condition appropriately in the harder periods as well. Only 52.2% of the Roma respondents declared the same. According to more than 50% of the respondents of both groups the GP asked nearly every time they met what an effect the chronic disease had on their life. From the answers of the

general population it turned out that the opinion of 45.5% was heard often, nearly always when the treatment plan was compiled. 34.8% of the Roma declared the same. However, 35% of them were almost never asked about their opinion.

In case of every disease examined by us the average of the PACIC scores of the general population was higher than that of the respondents living in Roma colonies (*Table IV*). As regards the average of the total PACIC scores, significant difference was found between the two groups in case of the diabetic patients and persons living with arthritis and chronic pain.

**TABLE IV.**

**Average scores of the PACIC\* questionnaire according to the diseases in the general population and among people living in Roma colonies**

Chronic diseases	Average of PACIC scores**		p-value (two-sample t-test)
	General population	People living in Roma colonies	
Diabetes	3.71	3.41	0.002
Cancers	3.59	3.55	0.139
Hypertension	3.50	3.39	0.088
Pain	3.48	3.25	0.002
Arthritis	3.53	3.33	0.024
Depression	3.55	3.39	0.069
Asthma	3.52	3.50	0.809

\*PACIC – Patient Assessment of Chronic Illness Care

\*\* Average of PACIC scores - The average scores of the answers to the 20 questions of the questionnaire related to the quality examination of the care

## DISCUSSION AND CONCLUSIONS

The risk of the development of chronic diseases greatly depends on the individuals' lifestyle and on the environmental effects which they are exposed to. According to the health survey of 2014 the vast majority of the Hungarian population live an unhealthy life. Smoking, excessive alcohol consumption, unhealthy nutrition and sedentary lifestyle play prominent role in the development of the cardiovascular, malignant and respiratory diseases (NEFI, 2015).

Health of the Roma population is even more unfavourable. Because of their health behaviour and lifestyle they are in an even more disadvantageous situation than the general population. Vast majority of them has low level of education, which factor is a high-priority one in the sphere of health education, health development, patients' instruction.

The primary aim of our survey was to examine the care of patients suffering from chronic diseases in the general population and among the Roma population living in colonies in Szabolcs-Szatmár-Bereg County. We carried out the survey by the help of the PACIC questionnaire, which proved to be a suitable measuring tool for the quality examination of the care of patients suffering from chronic diseases in the primary care.

A lot of surveys can be found in the literature carried out by the PACIC questionnaire (Glasgow et al., 2005; Piatt et al., 2006; Aragonés et al., 2008; Wensing et al., 2008; Gugiu et al., 2009; Drewes et al., 2012; Aung et al., 2014; Tusek-Bunc et al., 2014). In most studies the questionnaire was applied for the quality assessment of the care of a patients' group suffering from chronic diseases. In our research, however, by the help of the PACIC questionnaire we evaluated the feedback related to the care of patients suffering from one or more chronic diseases. In 2005 a similar survey was carried out by Glasgow and his colleagues in the US. By the help of the PACIC questionnaire they evaluated the opinion of 283 patients suffering from one or more chronic diseases in relation to their care (Glasgow et al., 2005).

**TABLE V.**

**Average total PACIC scores\* based on the distribution of the chronic diseases in the surveys carried out in the US and in Hungary**

	US survey N= 283	Total PACIC average*	
		Hungarian survey, general population N=721	Hungarian survey, people in Roma colonies N=477
Hypertension	2.62	3.50	3.39
Diabetes	2.83	3.71	3.41
Arthritis	2.67	3.53	3.33
Chronic pain	2.64	3.48	3.25
Depression	2.71	3.55	3.39
Asthma	2.40	3.52	3.50

\* Average of the PACIC scores - Average scores of the answers to the 20 questions in the questionnaire about the quality examination of the care

The average PACIC scores were higher in both examined groups of our survey than those in the US survey (*Table V.*). Among the listed chronic diseases the average PACIC scores were the highest in case of diabetes in both the US survey and the Hungarian one among the general population. This, supposedly, is owing to the fact that diabetic patients go to check-up examinations more often than people suffering from other chronic diseases. The significant difference between the results of the Hungarian survey and the previous survey made in the US originates from several reasons. The results might have been influenced by the different medical systems of the two countries, the different services rendered in primary care, the different subjective perception of the patients and their different expectations related to medical care.

We have to pay increased attention to the prevention and early diagnosis of the chronic diseases. The effective treatment of the diseases in the primary care would significantly contribute to the

mitigation and prevention of the complications' occurrence. The main consideration is that in the course of health education and patients' education, in the compilation of the treatment plan we have to take the patients' ethnicity, religious views, cultural values and folk traditions into account. The quality and individual care implemented within the primary health care will lead to the patients' satisfaction, to the improvement of the quality of their life.

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