

LIFE EXPECTANCY AMONG ROMA, ASHKALI AND EGYPTIANS

INTRODUCTION

Roma, Ashkali and Egyptian communities, of whom 70% live below the national poverty line, are particularly vulnerable to the cost of health care in Kosovo.

Solidar Switzerland together with partner Balkan Sunflowers Kosova took action to address the knowledge gap by conducting a health survey among the three communities in 2014. The full research findings and methodology will be available in separate publication¹.

Currently, there is not reliable statistical data on the life expectancy of the Kosovo Roma, Ashkali and Egyptian communities. In the absence of death statistics in Kosovo, we looked at the situation in neighboring countries. For example, according to a 2007 study, the Roma population in Serbia on average dies 10-12 years younger than the majority population². In country after country, this situation is repeated. This suggests that the Roma, Ashkali and Egyptian populations of Kosovo may also die considerably younger than people from other communities.

The main aim of the KOSANA Project is improvement of the health and social security of the population of Kosovo through support of active participation by civil society in the development and implementation of a health insurance system in the country.

The KOSANA Project empowers the CSO-s representing citizens and patients to create advocacy positions based on facts, information, and the needs of the people. This process requires a long-term effort and commitment by organizations that represent citizens' interests.

Kosovars' life span is around 70 years. I started getting more interested in this subject. I was surprised to find out that the average life span of our communities of Roma, Ashkali and Egyptians doesn't exceed 55 years. Living 15 years less than my Albanian and Serbian neighbours! I didn't receive it well; the classroom started spinning around in my head. I ask myself, why my community has such a short life, why should I live such a short life!?

Rrahim
Student in Plemetina
LIVES Film, 2014



1 New National Health Insurance Will Save Lives: Life Expectancy and Health in Kosovo's Roma, Ashkali and Egyptian Communities

2 Dragan Bogdanović, Dragana Nikić, Branislav Petrović, Biljana Kocić, Jovica Jovanović, Maja Nikolić, and Zoran Milošević. "Mortality of Roma Population in Serbia, 2002-2005." *Croatia Medical Journal* 48(2007): 720-726

In the BSFK survey, respondents provided information about their family members and close relatives who were deceased during the past ten years. The data analysis included: age of death, cause of death, regional differences in the age of death, mean differences between the three ethnic groups, to what extent the deceased

individuals were receiving medical treatment, and whether this had any impact on the age of death. To further investigate the low life expectancy, qualitative interviews were conducted with health care professionals.

KEY FINDINGS

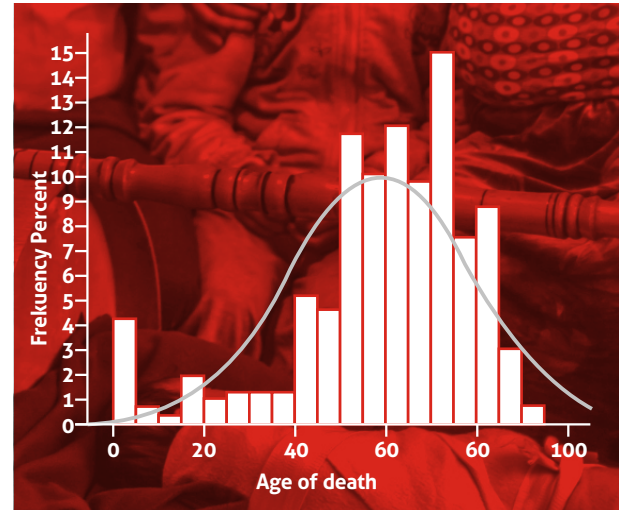
These are the main findings based on survey results:

1. The life expectancy of the Roma, Ashkali and Egyptian communities is less than 60 years, compared to the Kosovo average of 70.5.
2. The leading causes of death among the Roma, Ashkali and Egyptian communities are: stroke, cancer and cardiovascular diseases.
3. The majority of Roma, Ashkali and Egyptian households do not meet dietary recommendations. Poor diet is a contributing factor to poor health and low life expectancy.
4. Egyptians, Roma, Ashkali make almost no use of preventive health care services. There are also serious limitations in the utilization of curative services. The cost of treatment and medication together with the distance to the health care premises in some localities are major obstacles to use of health care services

Average age of death

The household survey collected information on 312 Roma, Ashkali and Egyptian individuals who had died during the past ten years. The mean age of death for this sample was 58.7 years and the median 63 years. The mean age of death for males was 57.4 years and for females 59.9. We estimate therefore that the life expectancy for the three minority communities is 11.8 years lower than the Kosovo average of 70.5 years³. The complete distribution of the ages of death is depicted in Figure 1.

Figure 1: Distribution of the ages of death



Of the 312 deceased family members, ten were infants who died before reaching their first birthday. Only two individuals reached age 90 or above. About one third (34.2%) of the sample reached age 70, the average life expectancy in Kosovo. We found no significant differences in ages of death among the three communities.

On the other hand, we identified considerable regional differences. For example, rural Ashkali, Egyptians and Roma live, on average, six years less than their urban counterparts⁴. The highest average age of death at 70 years was in Prizren city, where all the sampled households are urban. In contrast, in Gracanica municipality, the average age of death at 49 is more than 20 years less than in Prizren.

³ Life expectancy calculations to international standards is not possible as within the three target communities there is underreporting of both birth and death occurrences. Both forms of data are used in most authoritative calculations of life expectancy.

⁴ The regional differences in the ages of death should be treated with some caution since in 51.7% of the cases, the deceased individual did not live in the same household with the survey respondent.

Causes of death

The survey asked respondents about the causes of death of their deceased family members. The most common individual cause of death is brain infarction (stroke) with 68 cases, 21.8% of the sample.

Cancer was the second most common cause at 14.4%. Different heart diseases were the third highest cause of death with 10.2%. "Old age" or "natural causes" was reported for 41 (13.1%) cases.

Tabela 1: shkaqet e vdekjes

	Frequency	Percent
Brain infarction	68	21.8
Cancer	45	14.4
Natural	41	13.1
Heart diseases	33	10.6
Hypertension	19	6.1
Respiratory diseases	18	5.8
Other	16	5.1
Multiple diseases	13	5.2
Diabetes	12	3.8
Kidney diseases	12	3.8
Accident	11	3.5
Gastrointestinal diseases	11	3.5
Not known	7	2.2
Thrombosis	3	1.0
Tumor	3	1.0

Treatment coverage

The survey explored a hypothesis that the low life expectancy of the Roma, Ashkali and Egyptian communities is related to a lack of access to health care services. In 86.4% of the cases, respondents said that full medical treatment was available for the disease that is believed to have been the cause of death.

Respondents were asked if the treatment was affordable for the family of the deceased individual. In 46.5% of the cases, treatment was perceived as affordable for the family. A further 38.7% were able to afford the treatment partially. The respondents in 15.3% of the cases considered treatment unaffordable. We did not observe any significant difference in the affordability of treatment between localities or ethnic groups.

Based on these findings, we are unable to conclude that the low life expectancy of the Roma, Ashkali and Egyptian communities is resulting mainly from lack of treatment or inaccessibility of the health care services. To a certain degree, inability to afford medical treatment can help to explain low life

expectancy. In 54% of the cases, the deceased person was unable to afford full medical treatment for the disease or other problem that caused the death.

The qualitative interviews helped identify other possible reasons for the low life expectancy of the Ashkali, Roma and Egyptian communities. Many informants agree that problem is not the absence of treatment as such but failure to seek medical treatment at the early stage of a disease. In such cases, treatment of the disease is usually more difficult, more expensive, and has less positive outcomes.

Another serious problem that might affect life expectancy is an inadequate adherence to the medication regimen or other treatment. Dr. Slavisa Radosavljevic of Obiliq/Obilic, for instance, says it is common that his patients stop taking the prescribed treatment as soon as the symptoms begin to disappear. As a result, the symptoms may ease for a while but the disease will continue to persist. At some point, it will be too late to treat the disease with the limited resources available at a community health house.

The survey does not resolve to what extent inadequate or late treatment constitutes a problem in all Kosovo Roma, Ashkali and Egyptian communities though it provides support to presume this as a widespread problem. That said, we might question if over 85% of the deceased individuals had actually been receiving "full treatment" for the disease that caused their death or if that reported perception was very different than the reality.

"We have a problem that the Roma patients do not recognize the symptoms. Often, patients come to seek help at the more developed stage of their diseases. At this stage, treating a disease will be more difficult than at the early stage; in the worst cases, it is too late to provide any treatment. Some families have taken loans in order to pay treatment in a private hospital."

**Slaviša Radosavljević
Otorhinolaryngologist
Plemetina Health House, Obiliq/Obilic
Interview, 2014**

DISCUSSION AND RECOMMENDATIONS

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The survey findings support the observation that individuals belonging to the Roma, Ashkali and Egyptian communities have more than ten years lower life expectancy than their neighbors from the other communities.

Clearly, Roma, Ashkali and Egyptian communities are unable to enjoy “the highest attainable standard of health” as declared in the Constitution of the World Health Organization⁵. This is human rights issue that needs urgent intervention from the Kosovo authorities.

Life expectancy statistics for a nation and for subgroups is a normal and necessary function of government. It is functionally not available regarding the Ashkali, Egyptian and Roma communities in Kosovo because there is incomplete collection of several categories of relevant data: births, rates and causes of infant mortality, and reporting of other deaths and their causes. Hence, we are unable to provide more precise, scientifically backed estimates not only about life expectancy but also about the causes of death among the three communities.

Life expectancy is closely connected, of course, to the state of health. This is treated in the other policy briefs and research. We provide further recommendations for the national government,

local governments, international organizations, non-governmental organizations and the community actors in our four other policy briefs.

In order to address the issue of life expectancy, we recommend the following activities:

1. The government of Kosovo, local authorities and non-governmental organizations should investigate the extent of death registration among the Roma, Ashkali and Egyptian communities and identify the reasons for non-reporting of deaths.
2. The government of Kosovo should adopt such measures as needed to have full reporting of all deaths.
3. Policies implemented to increase reporting of deaths should also, to the extent possible, record the cause of death.
4. National and local health institutions should undertake exploratory or wider screenings for some of the most common mortal diseases to assess the possibility to increase early detection and intervention.

⁵ World Health Organization Constitution, 1954



Photo by Vedat Xhymshiti for Solidar Suisse Kosovo 2014