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Abstract

Background: Within the Balkan countries, data on the health of ethnic minorities are extremely scarce. This is especially true for the Balkan Roma, a reproductively isolated and socially disadvantaged and stigmatized population that has been historically underrepresented in health research. In this paper we present data collected on the health and health history of Roma women living in two communities in Serbia.

Methods: Personal and family health and reproductive histories were collected from 82 married Roma women, aged 17-67, who were living in two traditional, rural Roma settlements in northern Serbia. A strong focus was placed on investigating behaviours that could increase or decrease risk for chronic diseases (e.g., diabetes, cancer, cardiovascular diseases) in the females and their close kin.

Results: Results of this pilot study suggest that the Roma women face a high risk for certain chronic diseases, such as CVD and diabetes, but at the same time, may experience decreased risk for reproductive cancers. Further, Roma women distrust the health care system and use it infrequently.

Conclusion: The overall health profile of Serbian Roma women appears to be a result of cultural practices, with increased risk being associated with cumulative stress related to stigmatization, diet, patterns of physical activity, and lack of access to preventative programs. The decreased risk for reproductive cancers may result from their traditionally prescribed marriage and reproductive practices, which could have protective effects.

Background

The Roma are a diverse population of South Asian stock who, between the 9th and 14th centuries, migrated out of northwest India and into Europe (Fraser, 1992). At present, the Roma, one of the largest minorities in Europe, are concentrated in segregated communities characterized by poverty, unemployment, poor education, and poor quality housing. Although they have been residents of Europe for centuries, their integration into the social, economic, political and health care systems is poor. Ways to integrate this growing population into the European society are elusive (Uzunova, 2010).

The information available regarding the Roma is crude and suffers from lack of reliability. Accurate demographic and epidemiologic evaluation of the European Roma has been hindered by several factors. First, they are not a geographically stable population; they continue to be characterized by frequent migration. Further, the Roma, who often have faced stigma due to their ethnic origin, are often reluctant to accurately report that they are Roma.

According to a 2014 report prepared by the European Commission, the Roma population is increasing, as seen in their age structure. The average age of Europe's Roma population is 25.1 years, in comparison with 40.2 years for the EU states, a difference of fifteen years (European Commission, 2016). Despite this population growth, the Roma experience significant health disparities, which are closely linked to the social determinants of health including crowding in camps, poor living and socioeconomic conditions (European Commission, 2014). Across Europe, they experience lower life expectancy and have higher infant mortality. Although cancer is one of the two most widespread chronic diseases in Europe very little information exists about the prevalence of this chronic disease among Roma (Koupilová, Epstein, Holčík, Hajioff, & McKee, 2001; Ginter & Simko, 2011). A review of the literature on Roma health found only one

paper related to cancer (Aspinall, 2005). In this 1981 paper, a low incidence of cervical carcinoma among Roma women was found in the Karlovy Vary district of the Czech Republic (Hrajdek, & Petr, 1981). Reported incidence of cervical cancer was 26.2 per 100 thousand for non-Roma women, but only 2.4 per 100 thousand for Roma women.

The Roma living in the Balkans, when compared with other local populations, experience an increased risk of adverse metabolic conditions, resulting in their shorter life expectancy, high prevalence of obesity, metabolic syndrome, diabetes, cardiovascular disease, and low weight babies (Čvorović, 2014). In Serbia, Roma comprise around 8.18% of total population. Serbian Roma communities experience poor hygiene, high unemployment, low education, and are resistant to immunization programs (Čvorović, 2004; Save the Children, 2001). The limited data available regarding the health of Serbian Roma indicate that the prevalence of Type 2 diabetes, metabolic syndrome, and cardiovascular diseases in the Serbian Roma is higher than in the general population (Beljic Zivkovic et al., 2010). At the same time, the body mass index of the Serbia Roma is relatively high; in certain geographic areas a moderate to high proportion of individuals (~35%) can be classified as overweight while others approach at-risk levels for clinical obesity (Gallagher, & Strkalj, 2009). In 2002, the three most common causes of death in the Serbian Roma population were blood circulatory system diseases (390 or 44% of all deaths), malignant diseases (177 or 20%), and respiratory system diseases (56 or 6%) (Bogdanovic et al., 2007). However, these data, like all other existing sources of data, are inaccurate—mortality data were obtained from the 2002 Mortality Database and population data from the Population Census 2002, both of which grossly underestimated the number of Roma.

In Serbia, national health surveys regarding cancer incidence do exist but do not report ethnic breakdown (Vrdoljak et al., 2011). So far, only one research paper reports on the

reproductive health of Roma women living in Serbia. In this paper, a targeted health education project developed for Roma women in Serbia provided a gynaecological examination for 86 Roma women (analysing vaginal discharge or conducting a Pap smear, performing a colposcopic examination, a manual examination and a palpatory breast examination) (WHO Regional Office for Europe, 2010). Diagnosis revealed minor gynaecological issues and relatively good reproductive health for the Roma women involved. In sum, accurate data on the health of Serbian Roma are rare and the few serious research studies that have been done focus on small enclaves. In this paper we report on personal and family health histories of 82 Roma women living in Serbia. Plans are to expand this study to include a larger geographic area of Serbia and more Roma women in order to provide some formative data on their health and health risks.

Methods

Fieldwork was conducted in the fall of 2014, in two traditional Roma communities located outside of villages in Serbia's northern province. The Roma surveyed are the descendants of Roma who, after the abolition of slavery in Romania in the 19th century, settled permanently in the Serbian territories (Čvorović, 2004). Even though they have largely adopted the language and some of the customs of the surrounding majority they have retained many Roma traditions, including residence pattern. Which means they reside near their extended families, strong kinship systems and traditional marriage practices, which specify early endogamous marriage and strongly encourage all females to have large families.

There are around 120 Roma households in the first and 20 Roma households in the second village. The Roma residents live in houses that were poorly constructed, have poor sanitation, and are located at the outskirt of the villages. This residence pattern is typical for a Roma population. The majority of the adults in both settlements are unemployed, unskilled and

dependent upon social assistance and child welfare. Although there are elementary schools in the villages, Roma children rarely attend school and if they do attend school, they stay only for a few years. The majority of Roma women in both settlements are illiterate or semi-literate and none of the women are employed outside their homes.

Participants were recruited through personal contacts and local Roma organizations. Participants were eligible for this study if they were married with at least one child. The final sample consisted of 82 Roma women aged 17-67, who were interviewed face-to-face in their own homes. Interviews lasted approximately one hour.

Demographic information (e.g., age, educational level, marital status, socio economic status [SES], place of residence) was collected, along with information about marital and reproductive histories, diet and alcohol consumption, and health histories of self and family members. A focus was placed on asking about family history of diseases, especially cancer, and on behaviours related to health risk factors.

Results

The average age of the Roma woman in this study is 43.5 (±15.5); the majority of the women are between 48-57 years of age. The majority of these women never attended school and are illiterate or semi-literate. For those who did attend school, the average number of years spent in school was 3.1. (±2.87). Only six women (7.3%) completed compulsory elementary education, which is eight years. Around 51.2% (n=42) women rated their family status as poor (husband has no permanent employment), while 48.8% (n=40) women rated it as "a bit above poverty" (husband has seasonal job). In regard to access to social services and health care, 16% (n=13) reported having no personal documents-ID or health cards. However, around 55% (n=45) women reported that they did receive social help or child allowance.

In this sample, the average age of menarche is 12.2 years (the range from 10-15). These Roma women are married young, soon after menarche. The average age at first marriage is 15.3 (the range from 12-20). Reproduction follows soon after marriage: the age at first birth ranges from 11-29, with the average being 16.9 years.

The average number of children ever born to participants is 3.24 per woman; out of the total number of births, 5.1% children (n=13) died in infancy. Out of the mothers who lost babies, the majority (64%) claimed that they did not know the cause of death of their infants. The average gestation time per woman is 8.7 months; the children were nursed, on average, 12 months. On average, birth spacing is 2.21 years. Seventy-six percent of the women report having had an abortion and 71% of women report having at least one miscarriage.

Fewer than half of the women were old enough to be in the perimenopause. Data on the women reporting that they had passed through menopause (n=36) indicate that the average age at menopause is 46.2 years of age, with a range of 42-52.

Over half of the women interviewed (53.7%) reported that they never seek medical attention (see a doctor) when they are ill. Around 55% of the women reported that they did not see an obstetrician/gynaecologist during their pregnancies; 92.7% did not change their diet when pregnant and 63.4% reported that they smoked during their pregnancies. Five percent of the women consumed alcohol when pregnant and 96% reported that they were not physically active during their pregnancies. In this study, 63% of the Roma women report that they are active smokers (smoking one pack of cigarettes or more per day). The majority of the women reported that they are under "constant stress" due to poverty. Central among the concerns was the fact that they don't know "from where the next meal is coming from", a statement followed by another statement, indicating when you are Roma this is a "normal" state of affairs.

Out of 82 women who were interviewed, 53.7% (n=44) report being treated for a non-specified disease and these women describe their own health as "bad"; 46.3% rate their health as "excellent/good" (meaning they used no medications or received any therapy). The most common complaint is high blood pressure (32.9%), CVD (24.4%), diabetes (20.7%), and an unspecified "nerve condition" (11%), for which they report taking Bensedin (diazepam).

As far as cancer, only one woman (1.2%) reported being diagnosed and, at least in her mind, having successfully completed treatment for breast cancer three years ago. This woman is now 22 years old and pregnant with her second child (her mother died at the age of 57 from cervical cancer). No other women reported having any form of cancer.

The only variable with statistical significance, for the most common diseases reported by these Roma women by age category (for CVD p=0.000; for high blood pressure p=0.000 and for diabetes p=0.028). Age cohorts from 48 years of age, experience statistically significant risk for CVD, 38 years of age and up for high blood pressure while almost all cohorts are affected by diabetes, with those most affected being between 48-57 years of age.

As far as family history of illness, the most common diseases among the informants' mothers were CVD (20.7%), high blood pressure (22%), and diabetes (12.2%). Almost half of the women (47.6%) claimed their mothers' health was excellent/good (no medications/therapy) while seven respondents said they have no knowledge of their mothers' whereabouts or her health.

Twenty-nine informants reported their mothers were deceased, the most common reason being: "old age" (21.4 % said their mothers "died peacefully out of old age"), CVD (more than 30%), and complications related to diabetes (17.2%). Two women (2 %) said their mothers had been diagnosed with cancer (breast and cervix, cancer, respectively). These two mothers died as

a consequence of having these cancers; the one having breast cancer died after a surgery, due to infection stemming from improper post-operative care at home. The cause of death of their mothers was unknown to 14.2 % of the informants, and for the rest, the average age at death of the mothers was 63.82 (range between 47 and 81).

For the informants' fathers, the most common disease cited is alcoholism (38.5%) followed by CVD (26.9%); 26 informants reported that their fathers were deceased, the most common cause being alcoholism, CVD and old age (11%). The average age at death of the fathers was 60.46 (range between of 48-71).

Discussion

The Roma belong to the socially disadvantaged and ethnic minority groups that have been historically underrepresented in both anthropological and health research. Our data suggest several important points: the Serbian Roma women appear to be at high risk for many chronic diseases, but comparatively, they may be at decreased risk of ovarian and breast cancer. Furthermore, many Roma women do not use medical service or use it only occasionally when they are sick.

All Roma women agreed that the top health concerns in their communities are high blood pressure and heart disease, followed by diabetes and mental health issues, the same issues that were of concern for their parents. Alcoholism among their fathers is regarded as something "natural for a man". Among Roma, drinking and smoking are culturally and socially acceptable, and in this regard, they may be no different than other residents of Serbia. Serbia has the highest rates of smoking among adult women in Europe-- 33% of all women and 47.6% of those who are unemployed reported being current smokers (Markovic, Kesic, Topic, & Matejic, 2005).

The low incidence of cancer (1.2%) suggested by this study may be due to chance or due to the age of the participants and the small sample size -- only 82 women were interviewed, with the average age of 43.5. Cancer is usually considered a disease of aging, and the fact that Roma die at a much younger age than the rest of Europeans, may suggest they are dying before cancers develop. Still, given the low incidence of cancer and relatively good reproductive health also reported in the only two other studies available (Hrajdek & Petr, 1981; WHO Regional Office for Europe, 2010), some Roma traditional behaviours could be protecting these women from getting reproductive cancers. As is also found in Mormons and Seventh Day Adventists (Hulka, & Moorman, 2001), traditional Roma may be at lower-than-average risk due to their reproductive patterns, which include early age at first pregnancy, multiparity, duration of breastfeeding, number of incomplete pregnancies and early menopause. These variables can be combined into what can be referred to as "protected time", which is characterized as periods of anovulation, whereas ovulation inhibition has a protective effect. (Casagrande et al., 1979; Coe, Hess, & Swanson, 2013; Brewster, Stockton, Dobbie, Bull, & Beral, 2005; Maskarinec, Sen, Koga, & Conroy, 2011)

Culturally prescribed reproductive behaviour among traditional Roma are very different than those of the majority of Europeans. In traditional Roma communities, girls are married at an early age to ensure virginity and chastity, while high fertility appears as a social and gender obligation (Čvorović, 2014). In this sample, Roma girls are married shortly after menarche, and soon successive pregnancies follow, interrupted by breastfeeding of an average duration of one year and several abortions and miscarriages. After they complete reproduction, they enter menopause at the average age of 46, a lot earlier than typical European women, with an average age of 54 (Dratva et al., 2009). In fact, consistent with the results from this Roma sample, the

risks of cardiovascular disease and osteoporosis are higher for women with an earlier menopause, but at the same time, women who undergo an earlier menopause seem to experience some protection against breast cancer. As for cervical cancer, except for the number of women who report smoking (Mayo Clinic, 2003), women in traditional Roma communities may be at lower risk; given endogamous marriages and the fact both males and females are expected to confine their sexual behaviour to their marital partner (Čvorović, 2011).

While certain cultural practices among these Roma (e.g., smoking, physical inactivity, diet and failure to utilize services) can serve as risk factors for certain diseases such as diabetes, CVD, cervical cancer and high blood pressure, other cultural practices such as early marriage leading to early conception, high fertility rates, and breastfeeding can serve as protective factors and can help explain decreased risk for ovarian and breast cancer.

Due to the small number of Roma women participating, we are unable to generalize our findings beyond the population that was the focus of this study. Further, as we relied on self-report, the data on the health status of these Roma women may reflect only what the respondents say about their health, and should not be confused with factual health condition. Despite these limitations, this study still has implications for future research and practice. More research is clearly needed, that will include larger numbers and different Roma populations and will include interviews with local health care providers. Plans are now in development for expanding this study to a larger area in the Balkans but continuing to focus on females.

Statement of conflict of Interest

None of the researchers will be benefitting financially from the study or the publication. All authors in this study have no conflict of interests to report.

Adherence to ethical recommendations

We have observed appropriate ethical guidelines and legislation in conducting the study. Indiana University Institutional Review Board granted human subjects' approval.

Key Points

-Roma women have been historically underrepresented in health and anthropological research.

-Certain cultural practices among the traditional Roma women (e.g., smoking, physical inactivity, diet and failure to utilize services) can serve as risk factors for certain diseases such as diabetes, CVD and high blood pressure, other cultural practices such as early marriage leading to early conception, high fertility rates, and breastfeeding can serve as protective factors and can help explain decreased risk for ovarian and breast cancer.

- High levels of everyday stress due mostly to poverty impact the health profile of Serbian Roma women.

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