

REVIEW OF THE SCIENTIFIC LITERATURE ON THE HEALTH OF THE ROMA AND SINTI IN ITALY

Background: Roma and Sinti in Italy are excluded from the rest of society, often live in precarious housing conditions and have poor access to health services. In Italy, the Roma and Sinti minority (.3% of the overall population) is scarcely represented if compared with other European countries.

Methods: To establish what is known and how Roma and Sinti health is studied in Italy, we conducted a review of the scientific literature, including articles published between 2000 and 2010, found in Medline, Embase and Web of Science.

Results: We analyzed 15 relevant articles out of 32 references. Four papers describe rare autosomal recessive disorders. Four illustrate outbreaks of measles. The remaining papers describe health conditions suffered by this minority. All but two, however, are based on data collected at health services.

Conclusions: The lack of prevalence data and analysis of determinants is a detriment to the health of the Roma and Sinti populations in Italy. Participatory research and evidence-based interventions are needed to improve health outcomes and living conditions of the Roma and Sinti people. (*Ethn Dis.* 2012;22[3]:367–371)

Key Words: Gypsies, Roma, Sinti, Minority Health, Prejudice, Marginalization, Italy

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INTRODUCTION

Chronicles and direct experience indicate that Roma and Sinti living conditions in Italy are problematic. This is mostly due to Roma and Sinti living apart from the rest of society, in precarious housing conditions and with poor access to health services, employment and education.¹ From March 2010 to August 2011 seven children aged 1–13 years died in settlements for causes related to the precarious living conditions; a one-year-old child died from electrocution while the others died in fires in the shacks in which they lived.^{2–5} Population estimates report 170,000 Roma and Sinti,⁶ or .3% of an overall Italian population of more than 60 million.⁶ The Council of Europe estimates 11 million Roma, Sinti and Travelers living in Europe, which represents 1.3% of the total population of 825 million Europeans.⁷ About 50% of the Roma and Sinti living in Italy are Italian citizens (Italian Sinti, Italian Rom, Sicilian Caminanti and Harvati Roma). The remaining 50% are mainly citizens of former Yugoslavia (Bosnians, Kosovars, Serbs, Macedonians) and Romanians.⁶

There is considerable diversity among the different groups of Roma and Sinti living in Italy.⁸ In general, living and health conditions are not the same whether we compare Italian citizens, the long settled Roma migrants in Italy or the newly settled Roma migrants. Conditions also vary depending on the specific history of the settlements and communities, and the territories in which they are located. In addition, the media and many Italian political forces project a strong prejudice against Roma and Sinti people that influences institutional policies and the access of Roma to

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jobs, schools and decent housing.⁹ As anywhere else in the world, such inequality and the consequent marginalization of minorities can cause significant damage to the health of children and adults.

The aim of our review was to analyze published evidence on the health conditions of Roma and Sinti people living in Italy. The choice to focus our review on Italy allowed us to concentrate on the already quite heterogeneous Italian situation and may serve as a model for other European researchers to carry out similar reviews in each European country. We chose to focus on published scientific literature to obtain a more rigorous framework based on peer-reviewed studies.

METHODS

We conducted systematic literature searches of three medical and social electronic databases (ie, Medline, Embase and Web of Science - Science Citation Index and Social Sciences Citation Index). As the purpose of the study was to understand the current state of health among Roma and Sinti, we only included articles published between 2000 and 2010, without any study type or language restriction. The

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Medline strategy search was: Gypsies[MeSH] AND Italy. For Embase and Web of Science the terms Gypsies, Roma, Romá, Sinti, Travellers, and Nomads were used in association with the word Italy. The searches were conducted in March 2011. Two authors independently screened and selected the articles and analyzed the content. Disagreements in the decision to include or exclude identified articles were resolved through discussion. The terms used by the authors of the analyzed articles to identify the Roma and Sinti are reported between quotation marks.

RESULTS

The Medline search produced 14 references. In addition 18 references were identified from Embase and Web of Science searches. Five of the 32 references were duplicates. All the remaining 27 articles were retrieved in full-text (Figure 1). Twelve articles were excluded because they were not relevant to the objectives of our study: references and reasons for exclusion of the twelve

articles are available from the corresponding author.

Fifteen relevant articles contributed to our analysis:¹⁰⁻²⁴ four were published in Italian and 11 in English. No intervention study was identified. Four were case series,^{11,17-19} seven were cross-sectional studies,^{10,12,13,15,20,21,24} three were reviews or commentaries reporting original data,^{14,16,23} and one was a retrospective examination of clinical records.²² Since the identified articles were very heterogeneous, we decided not to carry out either a methodological quality examination or a meta-analysis and to focus on a qualitative synthesis of the results.

Of 15 relevant articles, four described autosomal recessive disorders affecting a total of seven Roma and Sinti individuals living in Italy.^{11,17-19}

Four articles illustrated outbreaks of measles and vaccination coverage. Two described a vaccination campaign conducted in 2002 in “sedentary populations of the Nomad Camps” in Rome.^{10,24} According to these authors, the vaccination campaign was justified by the low coverage among people

living in camps, the large turnover of difficult management for health services, the alarm issued by the World Health Organization after two cases of polio in the nomadic “nomade” Bulgarian population, and the precarious living conditions that worsen the course of infectious diseases.²⁴ Authors emphasized the semi-permanent character of Gypsy communities “comunità zingare” and their cultural barriers. Before the vaccination campaign, coverage varied significantly in the four areas managed by as many local health agencies (ASL). One article described a measles outbreak that occurred in 2006 in the nomadic population “popolazione nomade” of three Italian regions.¹³ The outbreak of measles that occurred in Merano affected the local Sinti community that has been in Merano for decades and does not have a nomadic lifestyle. The outbreak that occurred in Rome affected a Roma community of recently immigrated Romanians. Another article described two measles outbreaks in the Lazio region.¹² The authors highlighted the importance of pockets of low vaccination coverage in sustaining the spread of infection, particularly in the population of “Roma/Sinti” and undocumented immigrants.¹² However, the same authors made clear that the outbreak was possible because of nosocomial transmission, and incomplete vaccination coverage of the medical staff and the general population.

Gualdi-Russo et al described a study conducted in Bologna between 2000 and 2002, recruiting 401 immigrants aged 17 to 65 years from Senegal, Morocco, Tunisia, Pakistan, Kosovo and the Balkans.¹⁵ The sample also included 70 “Balkan Gypsies,” or “Roma,” 32 males and 38 females. The “Roma” had lived in Italy for eight years on average (only Moroccans had stayed in Italy longer), and had a low level of schooling, higher only than Kosovars. Among Kosovars, Moroccan and “Gypsy” males, there was a high

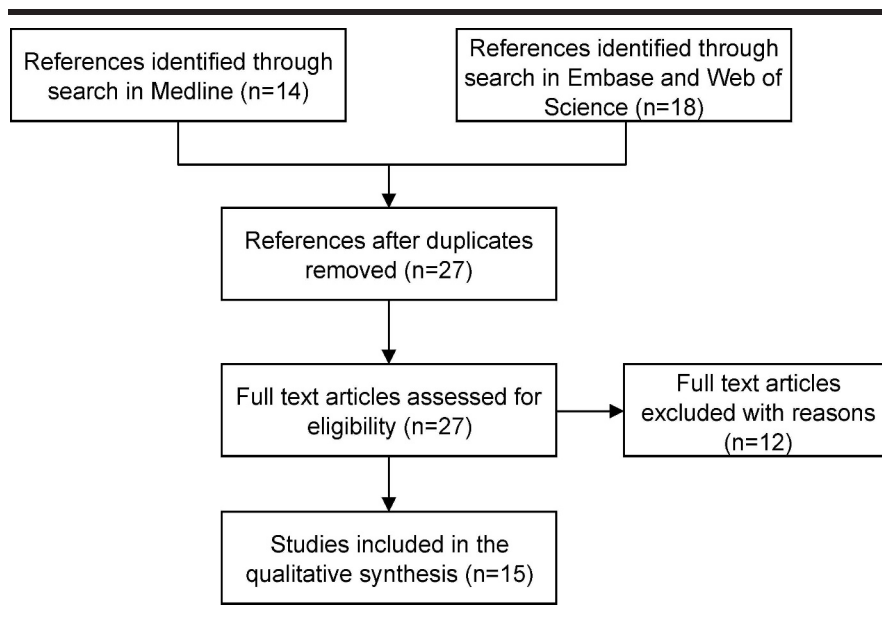


Fig 1. Flow diagram of references identified through database searching and included studies

prevalence of overweight and obesity (~60%), while “Roma” women, in contrast with other groups, did not have a body mass index higher than average Italian women. “Roma” males and females, compared with the other groups, had a higher risk of cardiovascular disease associated with hypertension among participants with waist circumference greater than 120cm for males and 88cm for females.

Morrone et al described 4941 medical examinations performed in 7 years (1996–2003) in about 50 “gypsy” communities in Rome, with a total population of around 4000–5000 people.²² The authors reported a high prevalence of dental, dermatological, gastroenteric diseases and traumas. However, since data were based on examinations, these should not be considered prevalence data. Finally the authors reported an increase in recent years in the number of cases of alcohol and drugs abuse.

Geraci et al assessed the health needs of Gypsy populations (“popolazioni zingare”).¹⁴ The major problems encountered by the authors were: a) the identification of the “popolazione zingara” in health statistics; b) that Gypsies are still partly nomadic; c) their insufficient and inadequate use of the national health system; and d) that identified studies targeted the poorest and most marginalized groups. The authors reported hospitalization data in Lombardy collected by Naga (non-profit association) in Milan in 1996, data of medical examinations collected by Caritas (non-profit association) in Rome in 1999–2001 and data on pregnancy and childbirth of the Epidemiological Observatory of Lazio. In Lombardy they reported high rates of hospitalization for acute bronchitis, streptococcal pharyngitis and intestinal infections, diseases due to unfavorable living conditions and hygiene, responsible for two hospitalizations out of three. Among adults, exposure to risk factors such as smoking, alcohol con-

sumption, coffee and unhealthy food (high content in fat and salt) caused high prevalence of hypertension. According to data from Caritas, the main reason for access to medical care was respiratory diseases, followed by check-up examinations in healthy patients and cardiovascular disorders. The high proportion of medical examinations done by Caritas for healthy patients and chronic diseases confirmed the attention to prevention and chronic asymptomatic disorders when services were available. The apparent indifferent attitude by the “zingari” population to prevention and chronic diseases was due to difficult access, high cost of treatments and complexity of procedures, and often by hard living conditions which generated more pressing needs. Data from the Epidemiological Observatory of Lazio showed a 18.4% rate of low birth weight in newborns (<2500gr) among nomadic populations (“popolazione nomade”) in comparison to 5.7% among Italians, a stillbirth rate of 9% vs 5.6%, a neonatal mortality rate around 15.1% vs. 7.5% and a mortality rate in the first year of 24.2% vs 9.4%. Considering the heterogeneity of the Gypsy population (“popolazione zingara”) in Italy, a clear definition of the population they referred to in this analysis is missing. With regards to the cited data from the Observatory, the authors do not explain how they identified mothers and children belonging to the “zingari/nomadi” category.

The Lancet published two articles dealing with the health conditions of Roma and Sinti in Italy.^{16,23} In a commentary, Sepkowitz mentioned the Italian situation, reporting that infant mortality is three times higher among Roma and Sinti than in the general population. However, the author quoted an article²⁵ that cites a report of the Open Society Institute²⁶ in which we could not identify the cited prevalence. The author might have referred to the data of the Epidemiological Observatory of Lazio reported by Geraci et al.¹⁴ A

World Report by Loewenbraum¹⁶ published alarming data from a previous report of the Comunità di Sant’Egidio (non-profit organization) on the prevalence of diseases and conditions such as malnutrition, low birthweight, bronchitis and asthma, skin diseases, gastrointestinal disorders, motor development and other disabilities. According to this report, the epidemiological causes of these conditions were poor housing conditions, social exclusion and widespread food insecurity. Unfortunately, these were not prevalence data as they referred to people accessing a clinic for diseases or generic medical check-ups (Dr. Ersilia Buonomo, personal communication, January 1, 2010).

In two articles, Monasta et al reported data from a prevalence study conducted between 2001 and 2002 in five Macedonian and Kosovar “Romá” camps, on the health conditions of 167 children from birth to age five.^{20,21} The aim of the study – understanding the relationship between living conditions and health of children under five years – was defined after visiting over 30 foreign “rom” settlements and asking people living in camps about their priorities. Research tools were refined during a one month stay in one of the five camps. The study found high rates of active asthma (7%) influenced by housing conditions. Within the 15 days prior to the study, 32% of children had had diarrhea, 55% cough, whereas 17% had had respiratory problems in the previous year, prevalence data comparable only to that found in refugee camps in war or conflict situations.²⁷ Risk factors associated with these conditions were number of years the family had lived in the camp, overcrowding, precarious housing conditions, use of wood stoves, and presence of rats in the area. During focus groups conducted with mothers, interviewees identified diarrhea, cough and breathing difficulties as the main child health problems related to environmental degradation, poor home insulation, presence of rats,

absence of adequate bathrooms and hot water, overcrowding and lack of safe playgrounds.

DISCUSSION

Regarding the four studies on autosomal recessive syndromes, data were collected on a total of seven patients living in Italy. As shown by a detailed report on the health of Gypsies in Spain, Roma and Sinti life expectancy in Italy is likely 10 years less than the national average, mainly because of social exclusion.²⁸ In light of these data, the fact that seven out of approximately 170,000 Roma and Sinti are affected by autosomal recessive disorders appears of limited relevance.

Another four out of 15 studies (27%) focused on outbreaks of preventable infectious diseases and vaccination campaigns. In our opinion, the studies had an overstated emphasis on the alleged nomadism and high mobility of Roma and Sinti. Almost no Roma or Sinti practice nomadism in Italy. High mobility is a feature of more recent immigrants and is often due to hard living conditions and policies of exclusion and forced eviction, and not to instinctive attraction to wandering. Extemporaneous vaccination campaigns do not lead to normalization in the relationship between Roma and Sinti and the health services. It is clear that there are no major barriers in the acceptance of vaccination programs by Roma and Sinti, and despite the emphasis on Roma and Sinti as vehicles of infection, outbreaks appear to be the result of low vaccination coverage in the general population.

Based on the reviewed articles, we surmised several conditions: 1) What is common to the Bulgarian Roma, the Sinti in Merano and the Romanian Roma in Italy, is not their being "Gypsies or nomads," but their belonging to a discriminated minority with difficult access to basic services. 2) What

distinguishes the different Roma communities in Rome with regard to vaccination coverage is not their mobility but rather the attention of different ASLs resulting in significant discrepancies in coverage among territories where camps are located. 3) It should not be argued that marginalized communities should be vaccinated to ensure infectious diseases are not spread; marginalization and poor access to health services should be systematically challenged.

We should also note that, in almost all cases in which diseases were described, data reported access to services and not prevalence of disease. This could indicate a lack of epidemiological door-to-door fieldwork.

Among the studies that reported situations of overcrowding and degradation, child health conditions tended to be dangerously close to those of their peers living in refugee camps in war zones. It is plausible that child mortality rates among Roma and Sinti could be significantly higher than the national rate. We would hypothesize that, with additional research of the Roma, Sinti, we would find a significantly lower life expectancy, a higher incidence of hypertension and risk of cardiovascular disease due to risky behaviors and stressful situations caused by exclusion and prejudice.

Our review shows a lack of data on the health conditions of the Roma and Sinti living in Italy, especially in terms of non-communicable diseases and their causes, and actual causes of communi-

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cable diseases' outbreaks and low vaccination coverage. Health needs, specific problems and service availability are extremely varied in different groups of foreign and Italian Roma and Sinti. Appropriate analyses are necessary to distinguish between different needs and problems and focus on interventions and policies.

Evidence-based interventions are also needed to improve health outcomes and living conditions of the Roma and Sinti people. Evidence should be gathered through participatory needs assessments, respecting and taking into account internal diversity. In our opinion, ethical committees evaluating research studies involving Roma and Sinti should consult members of their associations. Guidelines for research and interventions with Roma and Sinti communities should be defined in agreement with their associations in order to avoid carrying out studies and actions without complying with the priorities, features and conditions of Roma and Sinti.

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Acquisition of data: Monasta, Erenbourg, Restaino, Lutje, Ronfani

Data analysis and interpretation: Monasta
Manuscript draft: Monasta, Erenbourg, Restaino, Lutje, Ronfani

Statistical expertise: Monasta, Erenbourg, Restaino, Ronfani

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