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Incidence of infectious diseases and survival among the Roma population: a longitudinal cohort study

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Background: Roma ethnicity is greatly affected by tuberculosis (TB), AIDS, injecting drugs use (IDU) and imprisonment. **Methods:** We assessed the incidence of several health problems by means of a retrospective cohort study performed in Camp de la Bota, Barcelona (Spain). The 380 individuals included in the 1985 TB outbreak investigation were followed-up until 31 December 2008. One hundred ninety-two subjects (50.5%) were men and 188 (49.5%) women. Information sources included questionnaires taken at the time of this outbreak, a population census and other registries from Barcelona and Catalonia. Cox proportional hazards mixed models were employed in the multivariate survival analysis. **Results:** By the end of the follow-up, the survival rate was 79.4%; 50 persons (13.1%) had deceased and 28 (7.3%) had emigrated. The incidence of AIDS was 104 cases per 100 000 person-years of follow-up (pyf), IDU was 240 cases pyf, imprisonment was 642 cases pyf and that of TB was 91 cases pyf. Male survival was lower [hazard ratio (HR) 4.22], when the effect of family was taken into account, than when it was not taken into account (HR 3.67). **Conclusions:** High incidences of AIDS, TB, IDU, imprisonment and poor survival rates have been observed among Roma. Family was found to be an important factor influencing the survival rates: when not considered, the risk of death among men was underestimated.

Keywords: AIDS, imprisonment, Roma, survival analysis, tuberculosis

Introduction

The Roma population represent an ethnic group of 12 million individuals living in almost all European and American countries, as well as in some areas of Asia and Oceania. The precise number of Roma in the European Union is difficult to establish with accuracy. Estimates range from 3 to 7 million cited in the 2004 European Commission report to 10 million, reported in a 2008 European Parliament Resolution.[1] In Spain, the Roma community consists of people between 600 000 and 800 000.[2] Despite their poverty[3] and nomadism, the Roma have conserved part of their original culture, although they also have a history of marginalization and persecution. This is demonstrated by the slavery and murder they have suffered, notably as victims of the Holocaust.[4]

The few health studies that exist about the Roma show that their life expectancy is lower and infant mortality is higher than the general population.[5] The mean life expectancy of the Roma population in Spain was only 58 years.[3] One study reported that Roma women have a life expectancy of 6 years lower than men.[6] It was also observed that 47% of the scientific articles about the Roma population dealt with congenital malformations, paediatric diseases and transmissible diseases.[7]

In England, the health status of nomadic Roma was correlated to age, education and smoking, with higher rates of anxiety, respiratory problems, chest pain, involuntary abortions and mortality.[8,9] They are known to have poorer reproductive health than the rest of the population and a higher prevalence of infectious diseases, injuries and poisoning due to environmental causes. The premature death in this population is three times higher than in the general population.[5,10]

Socially disadvantaged groups are always greatly affected by transmissible infectious diseases.[11] In a study carried out in the Young Offenders Penitentiary in Barcelona, the highest prevalence of HIV infection was found among Roma drug addicts (70%).[12] In some settings, outbreaks of hepatitis have also been seen in families of Roma ethnicity with tattooing being a possible risk factor.[11,12] Given the poor living conditions of many ethnic minorities, tuberculosis (TB) is a concern.[13] In recent years, it has become clear that this ethnic group is not free of TB or HIV/AIDS, due to shortcomings in prevention and control, and the presence of risk

factors such as alcoholism, smoking and injecting drug use (IDU).[14–16]

Poor and deteriorated neighbourhoods can contribute to unhealthy living conditions. A TB outbreak was detected among Roma in Camp de la Bota, a marginalized neighbourhood of Barcelona in 1985, which gave rise to a contact study. A total of 20.5% had a positive tuberculin skin test and 14 TB cases (prevalence rate of 3.63%) were identified. This TB incidence was 115 times higher than the TB incidence rate of Barcelona in the same year. A total of five patients (a smear-positive father and his four sons) were living in the same shack.[17]

The objective of this study was to follow the Roma inhabitants of Camp de la Bota since the 1985 TB outbreak until 2008, analysing the incidence of infectious diseases, IDU, imprisonment and the survival in this population.

Methods

Design

A retrospective cohort study was performed.

Population

The cohort was composed of individuals identified during a TB outbreak investigation in 1985 in a Roma community called Camp de la Bota, Barcelona, Spain, as well as the new births until the settlement was removed in 1990. A tuberculin skin test was performed by public health nurses from the Barcelona TB Programme, in collaboration with nuns who attended the nursery, the community clinic and social centres in the neighbourhood. A thoracic X-ray was also performed for tuberculin skin test positive individuals. A total of 14 cases of active TB were detected (prevalence of 3.63%). The initial cohort included 427 subjects. Of these, data of birth was unknown for 27 (6.3%) and 20 (4.7%) were not known to be alive or dead at the end of the study (figure S3 of the online Supplementary Digital Content, SDC). These 47 individuals were excluded from the analyses. The cohort was followed-up from 31 December 1985 until 31 December 2008.

Information sources

The following registries were consulted: TB registry of Barcelona, communicable diseases and drug user registries of Barcelona and Catalonia, the Central Insurance Registry, the drug user register of the Catalan Autonomous Government Department of Health, the Penitentiary Services registries and the mortality registry of the Department of Health (to identify individuals who had died and their date of death).

Variables

The following variables were collected from the 1985 TB outbreak investigation: sex, date of birth, shack number and presence of TB. During follow-up, any additional names, place of residence, subsequent TB episode, HIV or AIDS diagnosis, IDU, type of drug, imprisonment, censored date and living status (date of death, if deceased) were also collected.

For data collection, we collaborated with a nun who worked in Camp de la Bota between 1974 and 1989 performing community work in the clinic as a nurse and in the nursery as a teacher. An epidemiologic questionnaire was administered for each TB case.

Statistical analyses

The mean, median and SD were calculated for quantitative variables. Frequency tables were used for qualitative variables. The incidences of TB, AIDS, IDU and imprisonment in cases per 100 000 person-years of follow-up (pyf) were calculated for the entire population as a function of gender and of city of residence. In each case, the denominator consisted of the sum of follow-up times since 1st December 1985 of the subjects under study. In case of newborns after that date, follow-up started at their birth date. Survival probabilities were calculated using the Kaplan–Meier method. For the multivariate analyses, the Cox proportional hazards model was applied to compare survival between men and women, using both the general model and the mixed effects model with family as a random effect. These survival analyses were applied to two distinct response variables. First, survival time was calculated as elapsed time since the beginning of the study, 1st December 1985. These times were potentially right-censored. Second, the life expectancy of this population was also of interest. For this purpose, age at death was modelled as the response variable; hence survival times were potentially right-censored and left-truncated (also called 'late entries').[18] In both cases, analyses were carried out taking into account these censoring/truncation schemes. We computed 95% confidence intervals (CIs) for finite populations. The proportionality of risks in the Cox models was verified graphically using a Schoenfeld residuals plot.

The statistical analyses were performed using the statistical package R (The R Foundation for Statistical Computing, Vienna, Austria), version 2.8.1. Incidence rates were calculated using the epitools library[19] and the survival analysis was performed using the survival library.[20]

Ethical considerations

All of the data are part of normal public health practise and, therefore, ethical approval was not required. The data were handled in a strictly confidential manner according to the principles of the Declaration of Helsinki, 1964, reviewed and updated by the World Medical Organisation (Edinburgh, 2000). The Spanish statute 15/1999 on data protection was followed at all times.

Results

A total of 380 individuals were included in the study, of which 192 (50.5%) were male and 188 (49.5%) were female. On December 1st 1985, the median age was 14.6 years (13.9 years among males and 15.0 years among females) and 25 cases (6.6%) were born after this date. The cohort was composed of a total of 65 families, living in 65 shacks, with a mean number of 5.7 inhabitants per shack at the beginning of the study (figure S5 of the SDC). A number was assigned to each shack to identify the residing family. During follow-up, 37 (19.3%) males and 12 (6.4%) females died. A total of 62 (16.3%) individuals were imprisoned (59.7% were males and 40.3% were females) and the median age at the time of imprisonment was 29 years.

In 2008, 19 years after the elimination of this marginal neighbourhood, the residential redistribution of inhabitants was as follows: 14.5% lived in Barcelona, 50.6% in the Barcelona metropolitan area, 25.0% had emigrated to other areas of Catalonia and the residence of 9.8% was unknown.

The follow-up showed that the AIDS incidence was 104 cases per 100 000 pyf, the incidence of drug addiction was 240 cases pyf, the incidence of imprisonment was 642 cases pyf and TB incidence was 91 cases pyf (table 1). TB was the AIDS-defining disease for five cases (62.5%). During the study period, two individuals presented with only TB, four presented with only AIDS and five had TB and AIDS. Twenty-six cases were IDU.

The survival analysis indicated that the probability of surviving at 20 years was 0.87. Survival was greater among women and worse among individuals >30 years of age (figure 1). The probability of death after 15 years of follow-up was 0.15 among males and 0.05 among females.

Figure 2 shows the global survival stratified by sex, with age at death as the response variable. The median age of death during the period of study was 68 years (figure 2) and higher in females than in males (86.7 vs. 56.8, respectively).

In the multivariate analysis, males' and females' survival was compared and adjusted for age (table 2). Model I analysed the time passed since December 1st, 1985 as a function of sex and age at the beginning of the study, including the latter as a continuous variable. According to this model, the hazard ratio (HR) for males vs. females was 3.59. The remaining models in table 2 show the age at death as the response variable, and treated data as right-censored and left-truncated. In this case, the only predictive variable was gender. Using this model, the HR estimation that compared males and females was similar to that of the previous model (3.67).

Finally, the use of the Cox proportional hazards model with family as a random effect and age at death as the response variable, revealed that the family effect increased the HR to 4.22, a higher risk than previously calculated. The family-level variance was 0.279. The Schoenfeld residual plots (not shown) demonstrated that the distribution of these residuals was random, confirming the validity of the assumption of proportional risks in these models.

Table 1 Incidence of TB, AIDS, imprisonment and injecting drug use according to sex and last living place in a Roma population. Barcelona (1985–2008)

	Cases	Follow-up (person-years)	Rate/100 000pyf[a] (95% CI)
Global			
TB	7	7702.7	90.9 (68.5–113.2)
AIDS	8	7686.3	104.1 (80.1–128.0)
Imprisonment	45	7009.2	642.0 (579.7–704.3)
IDU	18	7506.3	239.8 (203.0–276.6)
Men			
TB	3	3791.4	79.1 (49.4–108.9)
AIDS	5	3782.3	132.2 (93.7–170.7)
Imprisonment	24	3359.4	714.4 (619.5–809.4)
IDU	17	3359.4	506.0 (426.1–585.9)
Women			
TB	4	3911.3	102.3 (69.0–135.6)
AIDS	3	3904.0	76.8 (48.0–105.7)
Imprisonment	21	3649.8	575.4 (493.6–657.1)
IDU	1	3908.0	25.6 (8.9–42.2)
Last living place			
Barcelona			
TB	5	1097.3	455.7 (323.0–588.3)
AIDS	5	1070.9	466.9 (331.0–602.8)
Imprisonment	10	921.7	1085.0 (861.6–1308.3)
IDU	4	1044.0	383.1 (258.4–507.9)
Elsewhere[b]			
TB	2	6464.8	30.9 (16.7–45.2)
AIDS	3	6474.8	46.3 (28.9–63.7)
Imprisonment	35	5946.9	588.5 (523.8–653.3)
IDU	14	6321.7	221.5 (182.9–260.0)

a: Person-years
b: Place of residence in the follow-up

Discussion

This study has allowed us to establish that, after many years of follow-up, a marginalized population of Roma ethnicity presents poor survival and elevated incidences of AIDS, TB, IDU and imprisonment. These incidences (table 1) were higher than in Barcelona, where the rates of TB and AIDS during the same period (1987–2008) were 45 and 18 cases pyf, respectively.[21,22] Prison data also indicated that the rate of imprisonment in this population is higher than in the general population. Because 7.3% of the population below the age of 20 years had died after 17 years of follow-up, we conclude that this represents a high rate of mortality in our cohort. Barcelona's health report states that the mortality rate among young adults (15–44 years) in 1985 in our city was 126.9 in 100 000 men and 61.9 in women.[23] In our study, the life expectancy during the study period was 68 years (figure 2) and higher in females than in males (86.7 vs. 56.8, respectively). This number is below the life expectancy of being born in 1999 in Spain (78.9 years) or in Catalonia[3] (79.08 years for the whole population, 82.5 in females and 75.5 in males).

The median age was 14 years at the beginning of the study and the population pyramid of Camp de la Bota in 1985 by age and sex showed a young population structure, different from that of Barcelona (figure S4 of the SDC). This is characterized by the wide base and narrow peak of the population pyramid similar to that of low-income countries but different from Barcelona which has an older population structure.[17] Regarding other indicators in this cohort, only 17.1% of men

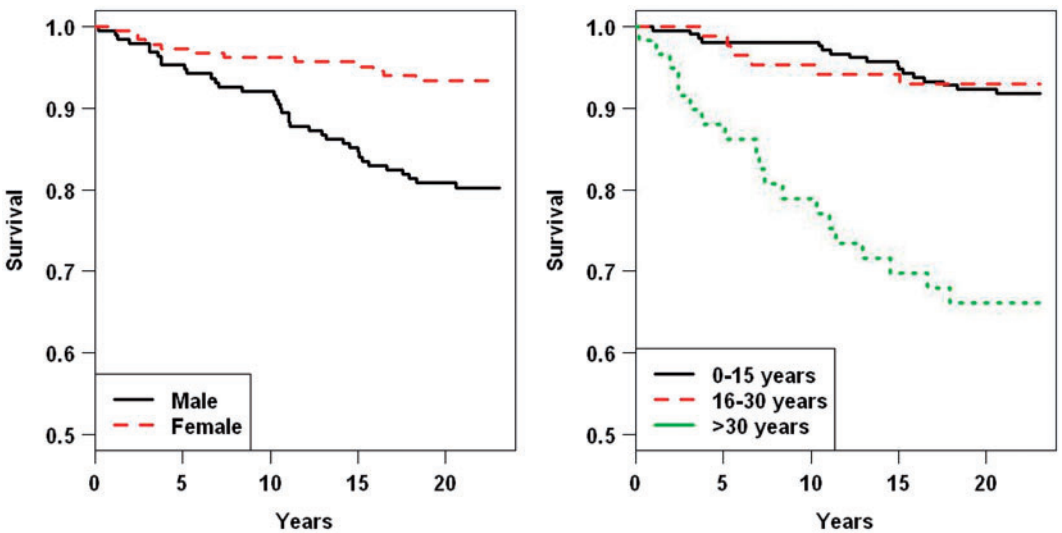

Figure 1 Survival according to various covariates in a population of Roma ethnicity. Camp de la Bota, Barcelona (1985–2008)

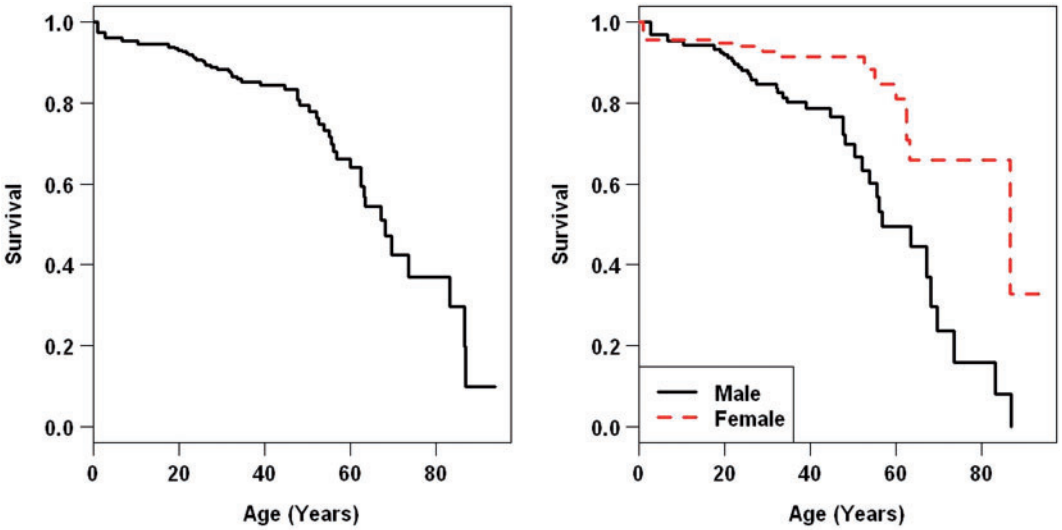

Figure 2 Survival using age at death as the response variable in a marginal population of Roma ethnicity. Camp de la Bota, Barcelona (1985–2008)

Table 2 Predictors of death according to a series of Cox models in a population of Roma ethnicity. Camp de la Bota, Barcelona (1985–2008)

	β	Se(β)	HR (95% CI)
Model I			
Men	1.277	0.333	3.59 (2.89–4.45)
Age	0.051	0.006	1.05 (1.05–1.06)
Model II			
Men	1.30	0.335	3.67 (2.95–4.56)
Model III			
Men	1.44	0.44	4.22 (3.17–5.62)
Model IV			
Men	1.41	0.43	4.10 (3.10–5.42)

Model I: Cox model with gender and age as covariates
Model II: Cox model with gender as covariate considering left truncation
Model III: Mixed effects Cox model with gender as covariate considering left truncation
Model IV: Mixed effects Cox model with gender as covariate considering left truncation, eliminating individuals without information on family

and 5.1% of women were employed. A total of 38.6% subjects were illiterate and higher among women than men (P. Pilar, Personal Communication).

In all developed countries, some groups or populations, such as ethnic minorities and individuals of low income, have greater burdens of health problems.[24] Poor health is a general reality for the Roma population. In fact, the Roma population is one of the most stigmatized and has high levels of social exclusion and poverty which affects education, employment, health, social and political participation, housing and prevalence of infectious diseases.[3] The high levels of poverty, lack of education, overpopulation and unemployment are probably principal causes, but little is known about the specific disease patterns and how these differ compared to other populations.[5,25]

The living conditions of this population have resulted in a general increase in drug use and crime, which translates in turn to imprisonment[16] and has repercussions on education and lifestyle.[5,26] Unemployment hinders social integration and explains many of the causes of death by accident among minority groups.[27] These realities have given rise to the definition of 'ethnification of poverty' and 'postmodern racism'.[28] Because of the marginalization of this group, many of the individuals in our study had problems with drug addiction (mainly heroin), such that they committed crimes just to survive, and leading to imprisonment. Syringe sharing also increases the risk of diseases transmission and poor survival.

The young Roma community suffers from these inequalities, with lack of access to education and health services, and poor use of these services when available.[29] The result is higher infant and youth mortality, illiteracy rates of up to 60% and high rates of IDU. One of the most common causes of morbidity among this population in Spain is transmissible diseases caused by poor living conditions and lack of use of preventive programmes.[16,26,30–33]

Although the analysis used for time elapsed since December 1st, 1985 produces valid estimates, using age at death as the response variable is more appropriate, since it permits interpretation of the results in terms of life expectancy. It is important to note that the family variable was not verified for all study subjects. Thus, in order to compare the random effects model with the previous one (without the random family effect), individuals with no family were discarded. In this case, the HR was 4.10. Given that Model V with random effects is valid, the missing family effect would result in underestimation of the differences between male and female survival. Therefore, we can confirm that family was an important component for estimating survival and that the males had poorer survival. It would also be interesting to explore whether a survival model that incorporates degree of relation between individuals within each family provides a better fit of the data. However, this was beyond the scope of the study.

A limitation of the study, which exists in all studies about the Roma population, is that follow-up is hindered by the fact that subject information is found under different names, shared names and many that do not appear in the registries. We also observed different incidence figures for different registries which indicate that information sources outside of Barcelona could have been misused during the study period. We also think that these results can be extrapolated only to other marginal Roma populations. Nonetheless, high incidence rates of IDU, imprisonment, AIDS and TB were present in our cohort, compared with the general population.

To intervene in these marginal populations, public health policies should focus on prevention and prioritize marginal populations for public health services.

In recent years, a number of political initiatives were proposed, such as the recognition of the Roma culture as integral and enriching. In 2003, a study of the Roma population was initiated with the aim of creating an integrated plan for assisting them in the Catalan Autonomous community. The approximate number of Roma in Catalonia in 1999 was 52 937 individuals, but the lack of a census data for this population and their nomadic tendency make it difficult to provide a reliable figure.[6]

Some Europe-wide decisions also have special importance. The European Commission has insisted on the need to eliminate social exclusion of all minority groups, to recognize the Roma population as a minority and promise actions and programmes confronting the exclusion of these populations. The National Reform Programmes (previously the National Action Plans) in many European countries also reflect this need, which now clearly address the underprivileged social and economic situation of the Roma population. In several countries of central and Eastern Europe, the Roma ethnic minority is officially recognized.[34]

Reducing health inequalities is a primary objective for the public health issues. This article as well as other information about Roma should favour specific public health interventions. Future research should take into consideration the use of a Cox model with random effects to accounts for family relationship. Ignoring the correlation of observations within the families may lead to an underestimation of the standard error.

In conclusion, the struggle to eliminate this population's exclusion from society and to avoid social marginalization is the first step to avoid these poverty conditions and thus prevent or decrease as much as possible infectious disease incidence. We trust that the year 2010, declared by the European Union as 'Year against poverty and social exclusion' will contribute to make these dreams a reality.[35]

Supplementary data

Supplementary data are available at *EURPUB* online.

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Key points

- Some Roma populations continue to be disadvantaged groups.
- We observed high incidence of infectious diseases, such as AIDS and TB, prison history and IDU in this cohort.
- All of these problems, in addition to social exclusion and poverty, explain the poor survival of this community.
- Public health policies should focus on prevention interventions directed at these ethnic minorities and the Roma population should always be one of the top priorities.

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