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# Illness behavior and cultural characteristics of the gypsy population in Spain

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Gypsy population constitutes the most important ethnic minority in Spain (more than 2% of population). Our country has the third largest gypsy population in the world. Although their presence among us dates from more than 600 years ago and their culture and their health needs are very different from ours, lack of interest about this group of population has been important. The growing migration process that has happened in our country during the last years has also produced an increasing concern about the health needs of gypsies. This paper aims to summarize the scarce present medical and anthropological knowledge on gypsies. The aim is to provide the health professionals with minimal skills to avoid possible prejudices towards this ethnic group and provide them high quality health care.

**Key words:**  
Gypsies. Epidemiology. Culture.

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## Conducta de enfermedad y características culturales de la etnia gitana en España

La población gitana constituye la minoría étnica más importante en España (más del 2% de la población), siendo nuestro país el tercero del mundo con mayor población total de gitanos. Pese a que su presencia entre nosotros data desde hace más de 600 años, y pese a mantener una cultura diferente y unas necesidades de salud muy específicas, el desinterés de los profesionales sanitarios por este grupo ha sido llamativo. El desarrollo de los procesos migratorios en España durante los últimos años parece haber desarrollado, secundariamente, una cierta preocupación por este grupo. Este artículo pretende resumir lo poco que se conoce a nivel sanitario y antropológico sobre los gitanos para poder dotar a los profesionales de unos mínimos conociemien-

tos que permitan disminuir los posibles prejuicios hacia esta etnia y poder ofertar unos cuidados de salud de mayor calidad.

**Palabras clave:**  
Gitanos. Epidemiología. Cultura.

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*Segregation is the consequence of an illicit relationship between injustice and immorality*

MARTIN LUTHER KING

## DEMOGRAPHY OF GYPSY ETHNIC GROUP IN EUROPE AND SPAIN

### Historic origin of the gypsy population

The written history of the gypsy population goes back to about one thousand years ago. In the XIX century, the theory of the Indian origin of the gypsy ethnic group gathered force because its language, «romani», was similar to sanskrit. This hypothesis is presently maintained based not only on linguistic considerations but on investigations on blood groups that have found genetic similarities between the gypsies and some Punjab tribes, in the north of India<sup>1</sup>. It is believed that the name of «gypsies» originated in a legend that states they made a pilgrimage from Egypt in penitence for having abandoned christianism.

It is believed that they arrived from India to the confines of the Byzantine Empire around the XI century and then settled down in Iran and caucasian region. They settled down in Asia Minor in the XII century and then in the geographic zone presently called Romania. The gypsies were spread over Europe after the fall of the Byzantine empire in 1493. There are written data that the first gypsies reached Spain, specifically Aragon Kingdom, in the year 1425, when King Alfonso V of Aragon signed a safe conduct for them to freely transit his lands. Initially, they were well-received in most of the European countries and they even requested papal protection as penitent pilgrims. However, this situation changed in the XVI century when, with the emergence

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of national European states, intolerance extended towards foreigners due to the religious wars in Europe because of the appearance of the Lutheran reform. After this, they were prevented from entering most of the European countries and were even expelled from some of them such as France, England or Switzerland. The situation became increasingly more negative for several centuries until during the XX century when more than half a million gypsies were exterminated in the Nazis concentration camps based on eugenic theories<sup>2</sup>.

At present, gypsies continue to exist on the fringe of society in Central and Eastern Europe, subject to institutionalized and widely extended racism. Although the communist regimes attempted forced assimilation after the second world war, offering some type of protection at that time, this disappeared in the 1990's. Racists attacks, often with semiofficial approval, increased. Even though there is no institutionalized discrimination in the Western countries such as Spain, the United States and others, gypsies suffer important obstacles to achieve real integration within the societies they live in.

## Gypsies in Spain and Europe

Estimations of the number of gypsies in the world greatly vary for two reasons: the first is that the history of oppression and forced assimilation they have suffered in almost all the countries makes them refuse to identify themselves as gypsies. The second is their itinerant life style and generalized mistrust in authority figures of the dominant non-gypsies ethnic group. In several European countries, their distinctive national identity was recognized in censuses for the first time in the first half of the 1990's. However, it is considered that the data on their number are not reliable in any country of the world because not all of the population is included in the census. In spite of these limitations, estimations suggest that the gypsy ethnic group accounts for approximately 5 % of the population of some countries of Eastern Europe such as Bulgaria, Hungary, Romania and Slovakia<sup>1</sup>.

In Spain, although there are no official censuses, it was calculated that there were between 650,000 and 800,000 gypsies at the beginning of the 1990's. This accounts for approximately 2 % of the population. These values, far from being insignificant, are close to those described in the countries in which the greatest percentage of the gypsy population exists, which we have described. In fact, it is considered that Spain would be the country of Western Europe having the greatest gypsy population and the third country in the world with the greatest total number of gypsies, only surpassed by Romania (about two million persons) and Bulgaria (with more than one million)<sup>1,2</sup>. In our country, the gypsy population would be made up mostly by gypsies who have suffered marginalization and acculturation processes

together with a small minority of hungarian and portuguese zingaros gypsies. The regional communities where they exist in greatest number would be Andalusia, Catalonia and Madrid, that are also the most populated regional areas. It is calculated that about 350,000 gypsies would live in marginal conditions<sup>3,4</sup>.

## Sociodemographic characteristics

The family nucleus of the gypsy ethnic group is generally stable. They are usually structured in extensive families and it is practically impossible, within the gypsy culture, for there to be persons who live alone or without family<sup>5</sup>. The family relationships are generally very close. Daily contact with family and friends is common. There is a very marked hierarchical order in the gypsy families: women and youth are on the lowest scale. The elderly are honored and respected and the youth care for their elderly family members. Family life includes many rules, and women have more rules to follow than men. The entire group participate in marriages and funerals. There are high rates of kinship, this being twelve times higher than in the general population. For example, marriage between cousins is more frequent among gypsies and that may be why a greater number of genetic disorders has been described in comparison with the general population<sup>6</sup>.

In regards to education level, illiteracy reached 41 % among the gypsies, 51% only can read and write and only 4 % finish primary studies<sup>5</sup>. Other studies are even more pessimistic and consider that illiteracy reaches 60 % of the total gypsy population<sup>7</sup>. The work situation also varies considerably according to the study group. However, in general, the number of gypsies with stable work is scarce. Most collect a pension or are unemployed without subsidy<sup>8</sup>. The gypsy population is a younger population, because life expectancy of this group is lower than that of the general population and there is a higher birth rate.

Investigations performed on the life style and economic situation of the elderly have observed that there is a loss of functions and separation from the family in highly industrialized Western cultures that does not exist in other cultures. However, in the gypsy ethnic group, the elderly live in the same home as their children and perform a series of functions and tasks within the family and clan, that become increasingly more important as age increases. In fact, the elderly have a crucial role in the conversation of old traditions<sup>9</sup>.

Degree of marginalization experienced by the gypsies in Spain depends on their place of residence. In recent years, they have tended to become grouped into periurban zones, outside the large cities, where their non-gypsy neighbors live in similar poverty situation and generally have the same situation of lack of resources and diseases. The gypsies have

higher fertility and child mortality rates than the general population<sup>10</sup>.

CULTURAL AND ANTHROPOLOGICAL FOUNDATIONS IN RELATIONSHIP TO HEALTH

Gypsies make up an ethnic group with specific cultural characteristics. In a broad outline, we would say that there are two groups of cultural norms that interest us from the medical perspective-those that are not related with health (but impregnate each group conduct) and those that are<sup>11</sup>.

Cultural aspects not related with health

There are a series of ethnic and moral values that are universally accepted by the gypsy community and modulate each conduct of this ethnic group. They are summarized in table 1.

Cultural aspects related with health

Health care providers frequently find cultural obstacles to offer optimum health cares and treatment to the gypsy population. At present, there is a great lack of knowledge on the access of gypsies to health services and on how they can be adequately offered. Understanding the sociocultural bases of the behaviors related with health is necessary to achieve effective and culturally competent health care. Gypsies, as any other ethnic group, have distinctive cultural beliefs and conducts related with health and health care. Knowledge of these characteristics and adaptation to the cultural differences are important in their health care<sup>13</sup>. As in the case of other ethnic minorities, the efficacy of the so-called «cultural mediators», well-trained persons who

know the gypsy setting and customs well, has been verified. They facilitate both the correct reception of the messages and adequacy of the codes used in the intervention<sup>14</sup>.

The ethnographic investigations in American gypsies have identified a strong conviction regarding beliefs related with health. These basic concepts influence all aspects of their daily life, including the way the gypsies deal with food and cleanliness, with doctors and hospitals, diagnosis of disease, seeking medical help or coping with birth and death<sup>15,16</sup>. Some of the main subjects regarding the health beliefs are the following<sup>15,16</sup>:

Diseases that are specific to the gypsies

According to these beliefs, some diseases are considered to be specific to the gypsy population. Thus they must be treated by traditional healers of their ethnic group. Others, on the contrary, are considered to be due to contact with the outer world and it is considered that they require formal health services. Presently, and due to the acculturation process with the non-gypsies, health and disease are interpreted in different ways in the gypsy population. The dominant perspective is a biomedical view of the human being. Another explanatory model of the disease reflects an attitude that agrees more with the Folk tradition that does not focus primarily on the physical body. It is said that the gypsies tend to interpret health and disease more from this latter perspective where destination, rituals and purification rules influence health and disease.

Purity

The way of life of the gypsies is structured by a series of rules about what is pure and impure. The border between both concepts is sometimes very diffuse. Being considered dirty is a disgrace and influences the rest of the daily life, which makes purification rituals very frequent. A woman is dirty, for example, when she has her period or gives birth, so that she cannot touch any element of the house. There are also a series of specific rituals related with birth, death and care of patients. These beliefs may lead the gypsies to accept some aspects of the non-gypsy care and reject others, conducts that are sometimes seen by the non-gypsies as irresponsible. For example, mental disease is considered impure, on the contrary to other diseases, and is thus generally hidden. This explains, for example, why the family does not visit psychiatric patients in the hospital when they are hospitalized, as occurs in physical illnesses.

Health cares

The cultural factors that may affect health cares include concepts such as contamination, cleanliness, ideal weight,

Table 1	Main ethical and moral values accepted by the gypsy culture <sup>12</sup>
Respect for the family as supreme institution of the gypsy society	
Care of children and elderly, the latter enjoying respect and maximum consideration	
Hospitality as obligation that should be manifested with pleasure and maximum attention	
Have honor, that means fulfilling one's word and fidelity to the «gypsy law»	
Sense of freedom as natural condition of the person	
Sense of solidarity and help for the members of the ethnic group as obligation	
Fulfilling decisions taken by the elders when these make them in compliance with the gypsy law	

death and prejudices on some of the medical procedures such as vaccinations or surgery. For example, if a gypsy is in the hospital, at least one family member must be there with him. The family clusters that come to visit the gypsies who are hospitalized often cause serious conflicts with the non-gypsy health care institutions. The only exception, as we have already explained, is that of mental disease. There are various meanings on the health cares that are dominant and specific for the gypsy culture. These are summarized in table 2<sup>7</sup>.

## HEALTH STATUS OF THE GYPSY POPULATION

In an editorial in 1997, McKee<sup>1</sup> spoke about this minority ethnic group, that lives in different countries of the world, and stated that their life style and health needs have been widely ignored by most of the communities. Some authors consider that the health problems of the gypsies are rarely described since they have traditionally been isolated from the rest of the population<sup>6</sup>. It is surprising that the health care managers and investigations have given so little attention to the gypsies' health needs, even though their distinctive life style suggests that their needs may be different from those of most of the population. This lack of interest becomes apparent when the term gypsy is looked for in Medline and more articles appear on a variant of the *Drosophila* fly than on the health of the gypsies.

There are two important bibliographic reviews on the publications existing in the scientific press regarding the gypsy group health. One is focused exclusively on the health problems of the Spanish gypsies. The other analyzes all the publications on the subject on an international level. It can be deduced from these articles that Spain has a very important place internationally on the biomedical investigation in the gypsy population. When the articles appearing in Medline on an international level on the gypsy ethnic group during the period from 1999 and 1999<sup>2</sup> are analyzed, and excluding opinion, anthropometry and genetic marker articles, approximately 70% of all the articles came from three countries. These are, in this order: Spain, Czech Republic and Slovakia. The subjects analyzed most in the international articles were transmittable diseases and child health as

well as sociodemographic studies and studies on risk factors in primary health care.

In the Spanish review, articles published from 1980-2001 on the health of Spanish gypsies were analyzed. These had mostly been published in Spanish journals. A total of 96 publications were found, 47 of which had been conducted in the last 6 years<sup>14</sup>. Most of the studies had been conducted in hospital sites. All had an observational design and 80% of these were descriptive. The most frequent subjects analyzed were: congenital abnormalities and transmittable diseases (30% and 21%, respectively) and in a lesser percentage, child health. Existence of inequalities in health was documented in more than half the studies. The Spanish regions where the greatest number were performed were Andalusia, Madrid and Catalonia, a phenomenon that may be explained because it is these regions of Spain where the greater number of gypsy population is accumulated<sup>14</sup>. It is interesting that the increase of articles on the gypsy population in recent years coincides with the increase of the immigration phenomenon in Spain. This has increased the interest on the study of the minority ethnic groups and, secondarily, on the gypsy ethnic group, that had been ignored for centuries.

One of the possible explanations why so little attention has been given to the gypsies could be that it is considered that conducting specific studies or taking special preventive measures could stigmatize them even more. This seems to have led to the fact that the idiosyncrasy of the group and their special needs have been forgotten, even excluding the fact that they belong to the ethnic group on their clinical history. On many occasions, this information is important, because it has an influence going from specific risk factors to biological characteristics in relationship to pharmacokinetics. In any event, the insufficient literature on this ethnic group limits the possibility of international comparisons. Although there are presently many investigations on minority groups of emigrants in different countries (for example, Asians in the United Kingdom, etc.), the health needs of many other groups have received little attention. In this sense, the gypsies are only one more group among the many unattended communities, although their situation is particularly difficult<sup>1</sup>. We will analyze the data available on the gypsy ethnic group in the different health areas in the following:

### General health

All the studies published on this ethnic group stress the existence of health inequalities. Knowing the inequalities is the first condition to be able to make adequate intervention designs on their characteristics. The few studies that exist suggest that their life expectancy is less than that of the general population, since child mortality is four times higher. The high levels of poverty, lack of education and unemployment found in countries that are so

Table 2

#### Meanings on health cares dominant in the gypsy culture

Care rituals must be provided when one is ill  
Protective cares are done as a group  
Gypsy values must always be respected, even during illness  
Moral codes and rules on pure and impure must be maintained  
One must be careful of strangers: gypsies are often suspicious of the non-gypsies and their insinuations, considering them as a focus of disease and impurity

far apart geographically and culturally such as Spain<sup>8</sup>, Turkey<sup>17</sup> and the United States<sup>18,19</sup> probably play an important role in this fact. However, we know little on their specific disease patterns and on how they differ from the rest of the groups.

In the Castellon health center<sup>8</sup>, an attempt was made to know and compare the sociodemographic characteristics and health condition of the non-gypsies and gypsies, with an observational, descriptive and cross-sectional study in which the two groups paired by age were compared. The results obtained were that there are statistically significant differences regarding educational level, profession and work situation, greater number of alcohol and parenteral drug consumers (in both cases, there are statistically significant differences between both groups, but not in the case of tobacco consumption) and early age of death (mean of 40.3 years in gypsies versus 73.3 years in non-gypsies). Paradoxically, there was a greater use of private medicine by the gypsies, their attitude to disease which was almost always interpreted as serious and urgent, constituting a possible causal factor. Due to this, they mostly come to the consultation on an urgent basis or without previous appointment, causing serious problems in the medical-patient relationship. The higher mortality rate in the gypsy group was due to infectious-contagious diseases (46.6 % of the total) while the main cause in the non-gypsy group was cardiovascular diseases (43.7 %). Other studies also suggest that the gypsies have a high incidence of medical diseases such as diabetes, hypertension, hyperlipidemia, obstructive vascular disease and heart disease, because there is a strong cultural base for the development of obesity, unhealthy eating and smoking<sup>18,19</sup>. They also seem to have a higher risk of lead intoxications and higher incidence of inherited congenital malformations<sup>20,21</sup>, that could be related with the already described frequent marriages to a blood relative.

### Use of health care resources

Evidence suggests that there is poor access to the health services and limited use of the preventive care, partially due to beliefs in destination and predestination, as causes of the disease<sup>1,2</sup>. For example, in a study conducted in the USA, it was shown that when these patients seek medical care, they frequently have a conflict with the health care staff who find their behavior confusing, demanding and chaotic. gypsies have maintained a closed society with an internal moral code and legal system. When they become ill, they have a significant dichotomy between primitive fear on the process of becoming ill versus a surprising sophistication for medical terms and the work of the hospitals<sup>18</sup>.

Women generally do not come to the consultation alone, but rather accompanied by family or friends. Gypsy women tend to have similar symptoms when coming to the consultation, certain complaints such as headache, neck and back

pain or depression predominating. Women generally come to the consultation when they have problems due to a special event within the gypsy community, for example, conflicts between the men or a noticeable non-compliance with the community rules<sup>6</sup>. The care pattern in gypsy women seems to have a recurrent character. In some periods, they may be seen very frequently (two to three times a week) and they tend not to go in other months. Another characteristic trait is the tendency of the women and their relatives to come to the health center chronologically, one after another. Then they generally express the same type of symptoms and often have the same diagnosis and treatment. Young women are especially vulnerable to develop these types of symptoms. Experience shows that women who are supported by their sisters handle their problems better and have greater possibilities of successful recovery<sup>6</sup>.

In the case of children, it has been seen that the number of hospital admissions and readmission rates in the hospital after discharge is greater than in the non-gypsy population, these differences being statistically significant. In a study performed in Valladolid, the socioeconomic and hygienic causes and health and educational differences were evaluated as a possible cause of the greater hospital readmission rates since the life style of the gypsy population confers less resistance to diseases<sup>20</sup>. Children are also brought to the emergency services more frequently. This may be due to the fact that they come to regular check-ups in their health care centers less frequently than the non-gypsy population<sup>21</sup>.

### Infectious diseases

Because they live in adverse socio-health conditions, the gypsy population has an increased risk of suffering tuberculous infection. They come to preventive programs, both regarding dental and gynecological health as well as pulmonary disease, less than the non-gypsy population. Their results are worse in all these programs, above all, in regards to lung disease<sup>22</sup>. One study conducted in Spain describes a nine times higher prevalence of hepatitis A antibodies in gypsy children than in the general population<sup>20,21</sup>. In adults, it is known that there is a greater proportion of hepatitis B and C virus and human immunodeficiency virus (HIV) infections<sup>8</sup>. When the clinical-epidemiological characteristics of the HIV infected patients seen as out-patients or in-patients are studied, comparing the gypsy, non-gypsy and immigrant groups, it is confirmed that the infection acquisition form was due to parenteral drug addiction in 95 % of the gypsies versus only 25 % in immigrants (in this group, most of the contacts are due to heterosexual contacts) and 70 % of the non-gypsies. It was also verified that the gypsies come to the out-patient clinics with the least regularity (only 48 %) versus 89 % of the non-gypsies and immigrants<sup>23</sup>. Table 3 summarizes the main sociohealth care characteristics of the gypsy population versus the non-gypsy one.



Table 3

**Socio-health care characteristics of the gypsies in Spain in relationship with the non-gypsy population<sup>8,18,19</sup>**

Lower level of education and employment. Greater frequency of invalidity  
 Lower life expectancy (mean of 43.3 years)  
 Main cause of death: infectious-contagious diseases  
 Infant mortality: four times greater than the non-gypsy population  
 Greater rate of alcohol and drug abuse (but not tobacco abuse)  
 Greater rate of HIV, HAV, HBV and HCV infections  
 Perceptions of the disease as serious: greater use of the emergency services and consultations without appointment. Greater use of private medicine

**Mental health and sexual behavior**

There are very few studies on psychiatric diseases in gypsies. As occurs in the immigrant population, it must be kept in mind that pharmacological effects of a substance may vary between the white population (in which most of the drug clinical trials are conducted) and the gypsy population, although there is no scientific evidence in this regards. There is only one study on suicide among gypsies, performed in non-nomadic population of three Hungarian cities. It reveals low consumed suicide rates, but a higher rate of attempted suicide compared with the general Hungarian population. The attempted suicide rate seems to be higher among the youth, above all among gypsies who have partially assimilated the country's culture. This produces a conflict between the traditional values of their parents and the combined Hungarian culture<sup>24</sup>.

A study was published in our country, specifically in Alava, on the subject of drug addicts in order to assess treatment compliance in gypsy patients with drug addiction within a maintenance program with naltrexone. A cohort study was designed, arranging the groups by age, gender, family support and HIV infection. The analysis showed that the probability of continuing with a prescribed treatment after a deintoxication period was higher among the «non-gypsy» group. Although the differences were not statistically significant, they showed a high tendency ( $p < 0.06$ ). The post-hoc tests showed maximum differences in compliance between both cohorts during the period of weeks 4 to 8 of treatment, differences that were not observed at other times in the study. A subsequent regression analysis of proportional risk showed a strong influence of the «previous treatments» variable. This effect was larger in the gypsy group, which finally caused a correction in the continuation curves that reduced the differences. If this correction had not been done regarding the previous treatment variable, it would have been considered that the gypsies comply less with the treat-

ments, which may cause certain prejudices among the professionals. They may even decide to not administer drug treatments or not refer them to specialized care. Thus, the need to establish informative and preventive measures aimed at understanding the idiosyncrasy of the gypsy culture to avoid prejudices among the gypsies is concluded<sup>5</sup>.

Regarding the culture and sexual behavior of the gypsy population, it has been verified that there are specific patterns in this regards. Only 61 % of the gypsy women use some type of contraceptive method, but irregularly. The number of abortions has increased and 33 % of the women have had at least three or more induced abortions. Because of the low level of sexual culture, and limited knowledge on contraceptive methods, the first pregnancy occurs at an early age and induced abortion rate is high. There is also a rapid demographic growth among the gypsies. That is, they have a greater number of pregnancies and induced abortions, with statistically significant differences in regards to the general population. This may be explained by tradition and life style of this population group, with a numerous family model<sup>25</sup>. The contraceptive method used most is *coitus interruptus* (with statistically significant differences regarding the other methods) and they ask for less contraceptive advice. Interestingly, it seems that the gypsy women know safe contraceptive methods, but do not use them for cultural reasons. Thus, specific family planning programs should be done for these groups due to the distinctive cultural and family traits they have<sup>26</sup>. Table 4 summarizes the main characteristics of the gypsy ethnic group in relationship to psychiatric disorders and sexual behavior.

**CONCLUSIONS**

Literature, opera or movies<sup>26</sup> on gypsies have projected an image of love of freedom and a mysterious life style. However, it has also accused them of causing significant social

Table 4

**Psychiatric aspects and sexual conduct of gypsy ethnic group compared with non-gypsy group**

Low rate of consumed suicides but higher rate of suicide attempts, above all in acultured youth in the non-gypsy culture  
 Less compliance to psychiatric treatments has not been demonstrated  
 Greater number of abortion than the non-gypsy population  
 They know contraceptive methods but do not use them due to cultural reasons. They use *coitus interruptus* significantly more. They ask for less contraceptive advice

problems. At present, they continue to be one of the few ethnic groups that still has not adapted to the general population. On the other hand, in spite of the renewed interest on immigrants in our country<sup>29</sup> and the emphasis on communication with the patient<sup>30</sup> and on the humanistic aspects of medicine<sup>31</sup>, interest about knowledge of this ethnic minority, which is the most important in our country, is scarce among Spanish health care professionals and among the general population.

In the growing literature on human rights of the gypsies in Central Europe, their poor health condition is often mentioned, however there is hardly more specific information. It is known that the health condition of the gypsy population is worse than that of the non-gypsy population, the transmittable diseases and diseases associated with hygiene being, above all, important. On the other hand, there is limited and inadequate communication between gypsies and health care professionals, preventive medicine being practically non-existent. Studies must be done on the health of the gypsies with special emphasis on the non-transmittable diseases and on the interventions that could improve the health of these populations<sup>28</sup>.

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