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Estimation of prevalence, incidence and sex ratio of transsexualism in Catalonia according to health care demand

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Objective. To estimate the epidemiology of transsexualism in the autonomous community of Catalonia according to data gathered at the Hospital Clínic of Barcelona, the single public hospital providing specialized psychiatric and endocrinological care for transsexual patients in this community.

Patients and methods. Prevalence was calculated on the basis of the total number of patients diagnosed of transsexualism (ICD-10, F64.0) at the Hospital Clínic and living in Catalonia, and the incidence by counting all new cases of transsexuals for the last 5 years, based on the population census between 15 and 65 years of age.

Results. During the period from 1996 through 2004 a total of 201 subjects were referred to this hospital with complaints of gender dysphoria. Transsexualism was diagnosed in 182 patients, 161 of whom were living in Catalonia. This yields a prevalence rate in Catalonia of 1:21,031 males and 1:48,096 females. The sex ratio was 2.6. Annual incidence in the last five years was 0.73/100,000/year.

Discussion. The low prevalence compared with recently published data from European Union countries may be due to the relatively few years of data collection and to the low clinical demand because surgical procedures costs are not covered by the public health insurance. In contrast, the high incidence may be due to the increasing demand since 2000, when a more benevolent and tolerant social climate in Spain started.

Key words:
Transsexualism. Epidemiology. Prevalence. Incidence. Sex ratio.

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Estimación de la prevalencia, incidencia y razón de sexos del transexualismo en Cataluña según la demanda asistencial

Introducción. Se realiza una estimación de la distribución epidemiológica del transexualismo en Cataluña se-

gún la demanda observada en el Hospital Clínic de Barcelona, que es el único hospital público que proporciona atención psiquiátrica y endocrinológica especializada a estos pacientes en esta comunidad autónoma.

Pacientes y método. La prevalencia se calculó según el número total de pacientes diagnosticados de transexualismo (CIE-10, F64.0) en el Hospital Clínic residentes en Cataluña y la incidencia en el número de pacientes con nuevo diagnóstico durante los últimos 5 años en relación con los datos de población de edad entre 15 y 65 años.

Resultados. Entre los años 1996 y 2004 solicitaron atención por disforia de género un total de 201 pacientes. Se diagnosticó transexualismo en 182 pacientes, de los cuales 161 vivían en Cataluña. La prevalencia estimada de transexualismo en Cataluña fue de 1:21.031 varones y 1:48.096 mujeres. La razón de sexos fue de 2,6 a favor del grupo de transexuales hombre a mujer. La incidencia media anual en los últimos cinco años fue de 0,72/100.000 habitantes/año.

Discusión. La baja prevalencia observada en comparación con los datos publicados por países de la Unión Europea se puede atribuir al período corto de recogida de datos y a la baja demanda registrada al no estar financiado el tratamiento de reasignación de sexo por el Sistema Nacional de Salud. La elevada incidencia se puede atribuir al incremento de la demanda desde el año 2000, que coincide con un clima social de mayor aceptación y tolerancia.

Palabras clave:
Transexualismo. Epidemiología. Prevalencia. Incidencia. Razón de sexos.

INTRODUCTION

Transsexualism, gender identity disorder or transsexuality, is defined according to the International Classifications of Diseases (ICD-10) and DSM-IV as a mental disorder characterized by a strong and persistent identification with the other sex, by a persistent discomfort with one's own gender and by a feeling of inappropriateness in the gender role,

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Table 1 Prevalence and sex ratio of transsexuality in different countries

Country	Years	Authors	Man to woman prevalence rate	Woman to man prevalence rate	Global prevalence rate	Sex ratio Man to woman/ woman to man
Sweden	1967	Walinder ⁸	1/ 37,000	1/ 103,000	1/ 54,000	2.8 / 1
USA	1968	Pauly ⁹	1/ 100,000	1/ 400,000		4 / 1
England and Wales	1974	Hoening and Kenna ¹⁰	1/ 34,000	1/ 108,000	1/ 53,000	3.2 / 1
Australia	1981	Ross et al. ¹¹	1/ 24,000	1/ 150,000	1/ 42,000	6.1 / 1
Singapore	1988	Tsoi ¹²	1/ 2,900	1/ 8,300		2.9 / 1
Holland	1980	Eklund et al. ¹³	1/ 45,000	1/ 200,000		4.4 / 1
Holland	1986	Eklund et al. ¹³	1/ 18,000	1/54,000		3.1 / 1
Holland	1993	Bakker et al. ¹⁴	1/ 11,900	1/ 30,400		2.5 / 1
Holland	1996	Van Kesteren et al. ¹⁵	1/11,900	1/30,400		2.5 / 1
Germany	1996	Weitze et al. ¹⁶	1/14,400	1/33,200		2.3 / 1

that causes deep psychological distress and significant impairment in the social, occupational area or in any other important area of functioning^{1,2}. The diagnosis is generally established when intersexual pathology is also ruled out, although there are exceptions in some cases of chromosomalopathies or hypogonadisms³⁻⁵.

Epidemiological studies of transsexualism are limited or null in most countries⁵⁻⁶. The first studies in the 1960's provided prevalence rates of 1/100,000 men and 1/400,000 women. Subsequent studies found progressively higher prevalences rates, and recent European studies estimate this at 1/11,900 men and 1/30,400 women⁸⁻¹⁶. These studies mostly find a prevalence of the sex ratio that is 2 to 3 times greater for man to woman transsexuals^{8,10,12-16} (table 1). In

most of the European countries, the incidence has been estimated between 0.14 and 0.26 for every 100,000 inhabitants and year^{10,16-19}, although it reaches values of 0.58 in Australia (0.58) and 1.58 in Singapore^{11,12} (table 2).

There is limited epidemiological data on transsexualism in Spain²². This has mainly been caused by the absence of public coverage for comprehensive treatment sex reassignment by the Spanish public health system until 1999. In that year, the Andalusian Parliament approved the comprehensive provision within the Andalusian Health Care Service for transsexual patients²³⁻²⁶. Since then, the demand for sexual reassignment by these patients has increased progressively, both in that autonomous community (AC) as in the rest of Spain.

Table 2 Incidence and sex ratio of transsexuality in different countries

Country	Years	Authors	Incidence/ 100,00/year	Sex ratio man/woman
England and Wales	1966-1968	Hoening and Kenna (1979) ¹⁰	0.17-0.26	1/1
Sweden	1967-1970	Walinder (1971) ¹⁷	0.15	1/1
Sweden	1968-1978	Landén et al. (1996) ⁶	0.17	1/1
Denmark	1970-1977	Sörensen and Hertoft (1980) ¹⁸	0.21	2.8/1
Sweden	1972-1992	Person and Ovesey (1979) ¹⁹	0.14	1/1
Australia	1976-1978	Ross et al. (1981) ¹¹	0.58	5/1
Poland	1974-1980	Godlewski (1988) ²⁰	—	1/5.5
Singapore	1971-1985	Tsoi (1988) ¹²	1.58	2.9/1
Germany	1981-1990	Weitze and Osburg (1966) ¹⁶	0.21-0.24	2.3/1
Germany	1970-1998	Garrels and Osburg (1966) ²¹	—	1.9/1
Sweden	1972-2002	Olsson and Möller (2003) ⁷	0.19-0.26	1.3/1-1.9/1

During the six years that the first Unit of Gender Identity Disorder has been functioning in Andalusia (Hospital Carlos Haya of Málaga), 448 patients (288 men and 160 women, sex ratio 1.6) have been seen, 417 in whom the diagnosis has been confirmed²⁷. Other medical teams of Spain have also provided related to health-care demand data, although not in centralized units. This makes the calculation of prevalence and incidence in the population difficult. In the Madrid AC, the demand data supplied from an endocrinology unit in the period between 1992 and 2004, both included, reached 402 patients (personal communication Becerra, 2005^{28,29}). Data collected in social and health care programs have also been supplied this AC³⁰.

In Catalonia, the Hospital Clínic of Barcelona is single public hospital that historically has seen these patients in the areas of psychiatry-psychology and endocrinology. This fact, and the limited experience of the private mental health care professionals on this disorder, places this hospital in a inwient position to evaluate epidemiological data on this disorder in Catalonia. Approximately 97 % of the patients who request or are referred for diagnostic or therapeutic assessment by mental health specialists are directed to this site. Since 2000, demand data have been systematically collected prospectively. The first sociodemographic, clinical and psychiatric descriptive studies of this population have been conducted³¹⁻³³.

The aim of this study is to evaluate the care demand by patients with gender dysphoria in the single public hospital of Catalonia where this care is praided to these patients, and to obtain an estimation of prevalence, incidence and sex ratio of patients diagnosed of transsexualism.

PATIENTS AND METHOD

The study sample includes by all the patients referred to the Psychiatry and Psychology Institute of the Hospital Clínic of Barcelona, becaused gender dysphoria complaints from 1996 to 2004, both included. The referral sources were mainly endocrinologists from the same hospital or in private practice to whom patients had gone requesting hormone treatment or private practice surgeons who had been requested to make sex reassignment surgery and/or by primary health care physicians.

Diagnostic evaluation of these patients was performed by one psychologist and one psychiatrist, according to the clinical guideline for the diagnosis and treatment of gender identity disorders published in 2003 by the Spanish Society of Endocrinology and Nutrition³⁴. The information was collected in a non-standardized semistructured interview where sociodemographic, clinical and psychiatric data, and specific data that include diagnostic criteria of transsexualism, were gathered. Diagnosis was confirmed during the follow-up visits. For epidemiological calcula-

tions, only patients who fulfilled transsexualism diagnostic criteria were included (ICD-10, F64.0)^{1,2}.

The health-care demand prevalence in Catalonia was calculated as the total number of patients diagnosed of transsexualism in the Hospital Clínic of Barcelona (1996-2004) who live in Catalonia, divided by the official population whose age ranges from 15 to 65 years registered in the year 2004 in Catalonia. The yearly incidence of the health-care demand in Catalonia was calculated as the number of new cases on the last 5 years, divided by the mean population in Catalonia for these 5 years. Patients diagnosed between 1996 and 1999 were excluded retrospective data collection. Population data were obtained from the Catalonia Statistical Institute (IDESCAT). The same calculations were made for the Barcelona population.

Data on the evolution of health-care demand, age birth place and residence site were analyzed.

RESULTS

During the period 1996-2004, a total of 201 patients with complaints of gender dysphoria were seen ($n = 147$ men; $n = 54$ women) (table 3) health-care. Demand increased in the year 2000 and was relatively stable until 2004 (fig. 1). A total of 182 patients ($n = 131$ of man-to woman; $n = 51$ of woman to man) were diagnosed of transsexuals, 161 of whom were residents in Catalonia. Mean age for the man to woman group was 29.8 years (standard deviation: 6.9; interval: 15-46 years) ($p = 0.002$). Age interval in which the most health-care demand was presented corresponded to 20 to 44 years for the man to woman subgroup and to 15 to 39 years for the woman to man subgroup (fig. 2).

The official population of Catalonia between 15 and 65 years in 2004 was 4,685,149 persons ($n = 2,376,538$ men and $n = 2,308,611$ women). The number of transsexual patients registered since 1996 who lived in Catalonia was 161 ($n = 113$ transsexuals from man to woman and $n = 48$ from woman to man) (table 3). Based on these data, the prevalence of transsexualism in this population was 1/21,031 men and 1/48,096 women. Sex ratio of prevalence was 2.6 in favor of the man to woman group. Given that most patients ($n = 155$) lived in the Barcelona province, if calculations weve based on the population estimated for 2004 for the previously mentioned age interval (1,996,708 men; 1,776,269 women), the prevalence data for the Barcelona province were 1/18,152 men and 1/39,473 women (table 3).

The health-care demand incidence recorded in the Hospital Clínic of patients diagnosed of transsexualism from 2000 to 2004 ($n = 161$), based on the mean population data of Catalonia ranging from 15 years to 65 years during these years (4,430,479 inhab.), was 0.73 /100,000 inhab./year. This corresponds to a mean of 32.2 transsexual patients/year.

Table 3 Prevalence data in Catalonia and Barcelona of transsexualism according to care demand in the psychiatry and Clinical Psychology Service of the Hospital Clínic of Barcelona

Residence site	Number of transsexual patients seen in the Hospital Clínic		15 to 65 old population in 2004	Prevalence
Catalonia (Barcelona)	Men to woman	N = 113	N = 2.376.538 men	1/ 21.031 men
		N = 110	N = 1.996.708 men	1/18.152 men
Catalonia (Barcelona)	Woman to man	N = 48	N = 2.308.611 women	1/ 48.096 women
		N = 45	N = 1.776.269 women	1/39.473 women
Rest of Spain	Men to woman	N = 15		
	Woman to man	N = 3		
Foreign country	Men to woman	N = 3		
	Woman to man	N = 0		
Total	Men to woman	N = 131		
	Woman to man	N = 51		

Sex ratio of the incidence was similar to that of the prevalence, 2.6.

Place of birth of these patients was Catalonia in 98 transsexuals (53.8%) (n=61 man to woman and n=37 of woman to man). The percentage of patients not born in Catalonia, mainly immigrants from South America, was significantly greater ($p < 0.005$) for the man to woman subgroup (n=32, 24.4%) versus the woman to man (n=3, 5.9%).

DISCUSSION

At the end of 2004, data collected in our hospital provided a prevalence rate of transsexualism in Catalonia esti-

mated at 1:21,641 men and 1:48,096 women. These data are approximately half of the prevalence reported by countries such as Holland (1/11,900 men and 1/30,400 women)¹⁵, Germany (1/14,400 men and 1/33,200 woman)¹⁶, or the AC of Andalusia (1/9,685 men and 1/15,456 woman)²⁷ and one eighth of that found in Singapore (1/2,900 men and 1/8,300 women)¹² (table 1). These studies were also performed using health care demand studies. There are several limitations that suggest that the health care prevalence may be underestimated regarding that of the general population. On one hand, in relationship with the prevalence of recent studies from other countries, we find greater values, however, most of these countries began to collect data in the 1960's. As the sample size grows over the years, prevalence increases until the number of

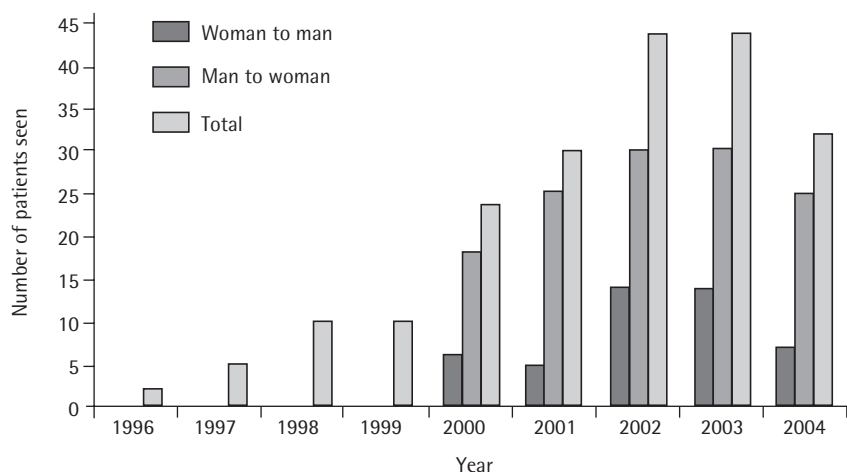


Figure 1 Evolution of gender dysphoria patient care demand in the Medical Psychiatry and Psychology Institute of the Hospital Clínic of Barcelona, based on year (retrospective data from 1996-1999, prospective data from 2000-2004, n = 201 patients evaluated).

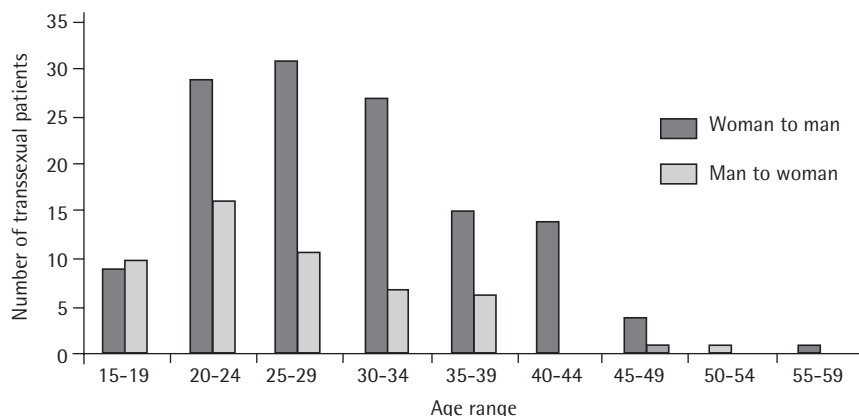


Figure 2 Interval of age variation of the patients diagnosed of transsexualism ($n = 182$) when they come to the Psychiatry Institute of the Hospital Clínic of Barcelona for the first time.

new cases of transsexuals tends to be equal to the number of deaths. Systematic registration of these patients did not begun in our hospital until the year 2000. Data with the greatest prevalence corresponds to countries with a social and health care environment more favorable to allowing transsexual patients to have sexual reassignment and assume the new civil status (Holland, Sweden and Singapore). In Spain, the transsexuality phenomenon has been marginalized for years. It was not until 1999 when comprehensive treatment was approved in Andalusia, and these patients then began to request medical care in the public health sector²³. However, lack of knowledge in a percentage of these patients about their problem, incapacity of some to support social rejection and lack of knowledge of expert professionals precludes the fact that not all these patients come to request help. The demand has been more than double in the Andalusia AC, with a slightly greater population than that of Catalonia and using a similar data collection period as ours (6 years versus 5 years)²⁷. In third place, because the health care coverage of Catalonia does

not include surgery, many transsexual patients do not request care in our hospital or request psychiatric assessment only when the private health care system surgeon requests it. In fourth place, when data are calculated regarding the whole population of Catalonia, most of the patients who request care were born in and live in Barcelona, but not in the other three Catalonia provinces. Thus, the epidemiological data approaches reality more when they have been calculated in regards to the Barcelona population and its metropolitan area (table 3). Finally, the age interval of the patients is low (few are over 45 years). However, the population chosen as a denominator for the calculations of prevalence includes the population between 15 and 65 years, due to its similarity to the calculations in other countries. If this denominator is restricted to the population, between 18 and 40 years, the data approach the more reality. Transsexuals over this age have often undergone treatment on their own account, or do not come to the health care system as they cannot complete the sexual reassignment process.

Table 4 Data of incidence of transsexualism in Catalonia according to care demand in the Psychiatry and Clinical Psychology Institute of Barcelona during the years 2000-2004

	2000	2001	2002	2003	2004	Mean in the last 5 years
New cases with transsexualism diagnosis	N = 24	N = 28	N = 39	N = 41	N = 29	N total = 161 en 5 años 32,2 patients/years
Population in Catalonia from 15 to 65 years	4,323,549	4,388,260	4,487,305	4,630,739	4,685,149	4,503,000
Incidence	0.56/100,000 inhabitants	0.64/100,000 inhabitants	0.87/100,000 inhabitants	0.89/100,000 inhabitants	0.62/100,000 inhabitants	0.72/100,000 inhabitants/year

The sex ratio the prevalence was 2.4, similar to that found in most of the European Union Countries^{8,10,14-16}, the USA⁹ and Singapore¹². Recent data from Belgium³⁵, Canada³⁶ and Andalusia²⁷ show only a slight predominance, between 1.2 and 1.7/1 in the man to woman transsexual group.

The incidence data in our study (0.73/100,000 inhabitants/year) 13 much higher than those found in most of the European Union countries (range 0.14 to 0.26/100,000 inhabitants/year)^{6-7,10,16-19} and are similar to data given in the Australia¹¹ (table 2). Comparison with these studies and other social-health care type factors in Spain establish limitations to these data and support the fact that the health care incidence data overestimate the incidence in the total population. Health-care demand in the Hospital Clínic has clearly increased since the 2000. This coincides with the beginning of the communication of the psychiatry and psychology professionals of this hospital with the main surgeons in Catalonia who are making genitoplasty and mastectomy in these patients, and also with some non-hospital endocrinologists who see these patients. It also coincides with a clear greater social acceptance in Spain since health care service was offered in Andalusia for its treatment, and with the creation and enhancement of the Associations and Foundations of transsexuals that provide information on the reference sites and medical specialists. Thus, it can be predicted that after an initial increase, the incidence data will be decreasing within a few years until reaching similar values to the European studies, given that the current data may correspond to a residual historic group that comes in search of health care.

The sex ratio of the incidence (table 2), as opposed to that based on prevalence studies (table 1), shows a mild predominance of man to woman group in the European and Asiatic studies. In Sweden^{16,17,19}, England and Wales¹⁰, this ratio has been found to be equal between both groups. Only one Polish study, with a small sample, found this relationship inversely²⁰. In our study, a 2.6 predominance persists for the man to woman transsexual group, which has remained constant in the last five years.

Mean age of the patients who came for the first time, as in the Andalusia study²³, is slightly older than the mean age presented in other European studies^{15,16,35,37-39}. In agreement with most studies, the woman to man transsexuals are younger when they request medical care for gender dysphoria^{5,39}. However, this information must be interpreted cautiously due to a confounding factor already analyzed in a previous study³¹. Women to men transsexuals are predominantly referred by endocrinologists and are in initial pre-treatment phases when they come. On the contrary, men to women transsexuals are mainly referred by surgeons immediately before the surgery because the reassignment process began years ago. This suggests that, on the contrary to the interpretations of previous studies, the

man to woman group initiates reassignment treatment at a younger age, very often with hormone self-treatment³¹.

The percentage of patients born outside of Spain is relevant, mainly in the man to woman subgroup (23%) usually in South America. In spite of this, the percentage of non-natives is lower than in Swedish and Dutch studies^{7,15,39-40}. Most of these patient live in Barcelona or in surrounding cities. This reflects, the migratory phenomenon to Catalonia and the better economic and social environment in Barcelona. The differences of sociodemographic data between countries are probably due to reasons such as the year of the study, methodological differences, different accessibility to gender reassignment surgery, different acceptance of both groups between countries. The Dutch, Swedish and Singapore societies show much more favorable attitudes than the rest of the countries.

The main limitation of this study is that it provides epidemiological data estimated from the health care demand, which is probably still far away from the real epidemiological data. Another limitation is that it is difficult to establish comparisons with data published in other epidemiological studies. Although most have been conducted in a clinical population, the type of services and criteria used as numerator and denominator are not uniform. Some define case as those who have been reached sex reassignment⁷, have requested legal name change¹⁶ or who are receiving hormone treatment, although most refer to those who receive the diagnosis of transsexualism^{21,14}. Although the denominator generally refers to the population over 15 years^{7,14}, other studies include the total population or the range of 15 to 65 years.

In spite of the limitations, the importance of this study is that reflects the current care situation and makes preliminary classification of problematic aspects of this social group, that has not been analyzed until recently. The fact that the Hospital Clínic is becoming consolidated as a reference site for transsexuality treatment in Catalonia will favor the possibility of continuing studies in the near provides can accurate future as it to all the population of a community and it supplies more data. The perspective that the public health system may assume the integrated treatment of sex reassignment, including surgery⁴¹, a greater facilitation of the legal aspects, and greater social sensitization and acceptance of this disorder will be the main factors that will undoubtedly make it possible to provide more real data on the epidemiology and perhaps to gather solid, data in agreement with other European studies.

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