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Health-care disparities stemming from sexual orientation of Italian patients with Multiple Sclerosis: A cross-sectional web-based study



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ABSTRACT

Lesbian, gay, bisexual and transgender (LGBT) patients might experience unique difficulties and barriers to treatment of chronic diseases related to their sexual orientation. Thus, we investigated concerns experienced by LGBT patients with multiple sclerosis (MS). We conducted a web-based survey using a multi-choice questionnaire published in an Italian social-network (www.smsocialnetwork.com) for MS patients. The survey investigated: socio-demographic factors, lifestyle habits, MS-related health status and LGBT specific issues (e.g. friendliness to their sexual orientation and eventual homophobic behaviors in the MS Center). Among MS patients willing to use psychological services, LGBT patients were associated with a smaller number of psychological consultations, compared to heterosexuals (Coeff.=-0.449; p < 0.001; 95%CI=-0.682 to -0.217). LGBT patients were more likely to change MS Center, compared to heterosexuals (OR=2.064; p=0.046; 95%CI=1.011-4.212). The number of MS Center changes was associated with MS Center friendliness (p=0.037; rho=-0.229) and with the occurrence of homophobic behaviors (p=0.036; rho=0.234). LGBT MS patients more frequently changed MS Center and had a reduced use of psychological services, compared to heterosexuals. The attitude towards LGBT MS patients might affect resource utilizations and LGBTs health status.

1. Introduction

Patients' confidence and trust in the attending physician affect willingness to discuss sensitive medical issues and medical care strategies for the management of different diseases. In this context, there is a growing body of evidence showing that lesbian, gay, bisexual and transgender (LGBT) patients are prone to experience unique difficulties and barriers to treatment (Coren et al., 2011; Minnis et al., 2016). In fact, they face well-documented health-care disparities, such as lower levels of preventive health behaviors (i.e. physical activity or diet), and poorer health outcomes, with elevated rates of psychiatric and physical diseases (i.e. depression or obesity) (Minnis et al., 2016; Daniel and Butkus, 2015).

Discriminatory behaviors in clinical practice have been suggested as a possible reason for LGBT avoiding health-care providers and/or having poor compliance with medical recommendations, fearing a homophobic setting (Dorsen, 2012; Khalili et al., 2015). Therefore, appropriate policies have been strongly encouraged to achieve equity

for LGBT persons in health-care systems (The Lancet, 2016; Daniel and Butkus, 2015; Bränström and van der Star, 2015).

Nevertheless, little is known about concerns experienced by LGBT patients with chronic disorders, such as Multiple Sclerosis (MS), a neurological disease affecting young adults and requiring life-long multidisciplinary cares (Rosendale et al., 2015; Bränström and van der Star, 2015; Foglia and Fredriksen-Goldsen, 2014). We hypothesize that these patients might experience health-care disparities due to their sexual orientation (Rosendale et al., 2015). Therefore, the present webbased cross-sectional study aims at investigating: 1) health-care disparities between LGBT and heterosexual MS patients; 2) sociodemographic and clinical features associated to health-care inequalities; 3) occurrence of homophobic behavior and/or heterosexist attitudes in the MS management.

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2. Methods

2.1. Study design

The present study investigated differences in socio-demographic characteristics, clinical features and health-care utilization patterns between LGBT and heterosexual MS patients, with a cross-sectional design. We conducted a web-based survey using a multi-choice questionnaire (see "data collection") published in an Italian social-network created by I Clinic of Neurology of Second University of Naples (www.smsocialnetwork.com), where patients with MS can exchange information monitored continuously by several medical MS experts (Lavorgna et al., 2014; Moccia et al., 2016a). At the time the study was conducted, the web-community included 1004 users.

Considering the estimated prevalence of MS in the Italian population, a sample of 300 patients was considered representative (α =5%, 95% Confidence Intervals) (De Waure et al., 2016). Furthermore, a response rate over 10% has been considered as an indicator of data quality for social network-based studies (Alshaikh et al., 2014).

The study was performed in accordance with good clinical practice and the Declaration of Helsinki. All participants consented to the use of recorded questionnaires for scientific purposes on aggregate level. To protect the anonymity of the participants, the Internet protocol codes of the computers were not registered, and no electronic "cookies" were embedded.

2.2. Population

We recorded questionnaires from 307 MS users/patients. We decided to exclude questionnaire with incomplete answers (5 questionnaires) or from users/patients under 18 years of age (2 questionnaires). Therefore, questionnaires from 300 users were included in the final analyses. Among these, 11.6% (n=35) reported as being LGBT: 13 homosexual females, 14 homosexual males, 7 bisexual females, and 1 bisexual male. There were no transsexuals among the MS patients participating to the social network and included in the present study. Socio-demographic characteristics, clinical features, and use of healthcare services are reported in Table 1.

Table 1 Socio-demographic and clinical features of the MS population. Socio-demographic characteristics, clinical features and use of health-care services are reported for the MS population, and are compared between LGBT and heterosexual patients. Results are reported as mean \pm standard deviation for continuous variables, or as number (%) for discrete variables. P-values are shown from t-test, χ^2 test, or Fisher's exact test, as appropriate (*p < 0.05).

	LBGT (<i>n</i> =35; 11.7%)	Heterosexuals (n=265; 88.3)	p-values
Age, years	35.2 ± 8.7	39.8 ± 9.8	0.008*
Gender, female	20 (57.1%)	172 (64.9%)	0.369
Education			0.200
Primary school	3 (8.5%)	55 (20.7%)	
Secondary school	20 (57.1%)	137 (51.7%)	
University	12 (34.4%)	73 (27.6%)	
Changed their MS center	20 (57.1%)	104 (39.2%)	0.043*
Diagnostic delay, years	2.3 ± 2.9	2.7 ± 4.9	0.579
Number of DMTs	2.3 ± 1.5	1.9 ± 1.3	0.143
Relapsing course	26 (74.2%)	219 (82.6%)	0.230
Neurological visits	2.8 ± 1.7	2.8 ± 2.4	0.981
Blood samples	5.8 ± 7.8	4.5 ± 4.4	0.160
MRI scans	1.2 ± 0.9	1.3 ± 0.9	0.682
Other medical visits	1.1 ± 0.9	1.4 ± 1.3	0.234
Use of psychological services	5 (14.2%)	76 (28.6%)	0.071

 $\operatorname{MS:}$ Multiple Sclerosis; LGBT: lesbian, gay, bisexual, transgender; DMTs: disease modifying treatments.

2.3. Data collection

The survey was publicly available on-line on www.smsocialnetwork. com, from October 5th to November 27th, 2015, where it was shared among MS patients. The questionnaire was composed of 32 multichoice questions derived from studies investigating health-care issues in LGBT populations and specifically selected in consideration of their relevance, as emerged in previous studies (McCann and Sharek, 2014; Sharek et al., 2014).

Taking into account that the selected questions were previously used in LGBTs but never in MS patients (McCann and Sharek, 2014; Sharek et al., 2014), the final version of the questionnaire was tested for both the content and the understandability on five LGBT MS patients, recruited thanks to an Italian LGBT organization (www.gay. it), who gave a positive feedback, describing the survey as appropriate for LGBT MS patients.

The questionnaire was related to three main topics: socio-demographic factors and lifestyle habits; MS-related health status and health-care services and, finally, LGBT specific issues (the full questionnaire in Italian language is available as Supplementary Material).

Socio-demographic characteristics (age, gender, educational attainment and working position) and lifestyle habits his will soon become a major issue as more and more government agencies make the switch to the Linux platform as their default desktop. (e.g.: physical activity, smoking, alcohol and illicit drug consumption) were recorded. Moreover, sexual orientation was assessed using the 2013 National Health Interview Survey (Minnis et al., 2016).

Then, with specific regard to MS-related health status and healthcare services, the questionnaire included following records: 1) age at disease onset and at diagnosis (the delay in diagnosis was subsequently calculated); 2) current disease course (relapsing-remitting or progressive); 3) walking difficulties; 4) current and previous disease modifying treatments (DMTs); 5) number of medical visits (e.g.: neurologist, ophthalmologist, urologist, psychological evaluations, etc), and laboratory or neuroimaging examinations related to MS (i.e. blood samples, MRI scans) within the past 12 months. In addition, patients were asked for: a) the number of MS Centers changed during the course of disease; b) reasons for the change of MS Center (e.g. poor alliance with the physician, change of address or difficulties in reaching the center). The questions were integrated with a short medical term explanation to be easily accessible to all participants. Questions were extracted from previously used scales in web-based surveys on MS patients (Jongen et al., 2015).

Finally, nine questions using a five-point Likert scale-type (from 1 -strongly disagree- to 5 -strongly agree) evaluated the MS Center friendliness to the LGBT sexual orientation (McCann and Sharek, 2014; Sharek et al., 2014). Finally, homophobic behaviors in the MS Center were investigated by five binary questions. The average number of homophobic behaviors was subsequently calculated (McCann and Sharek, 2014; Sharek et al., 2014).

2.4. Statistics

Means and proportions of socio-demographic characteristics, clinical features, and use of health-care services were calculated for the whole MS population included in the present study and, then, for LGBT and heterosexual patients. Study outcomes were selected considering results from exploratory analyses. Differences between LGBT and heterosexual patients were evaluated with t-test, χ^2 test or Fisher's exact test, as appropriate. Therefore, for the selected outcomes, multivariable logistic regression models were used to explore associations between being LGBT and binary variables (i.e. decision to change MS Center, or use of psychological services). Multivariable Poisson regression analyses were used to explore associations between being LGBT and count variables (i.e. number of MS Centers, or number of psychological consultations). Covariates considered for the analyses

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