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TWOFOLD DISCRIMINATION OF WOMEN WITH RARE
DISEASES

Emilia Moreno Sánchez (a)*, José Antonio Rodríguez Mena (a), Cristina Tiernes Cruz (b)
*Corresponding author

(a) Education Department. Faculty of Education, Psychology and Sports Sciences. University of Huelva-Spain

(b) Golden West College, Huntington Beach. California

* Email: emilia@uhu.es

Abstract

The purpose of this work is to establish the ongoing need to carry out training activities and research from a gender perspective, both in psychosocial aspects and in the biomedical, epidemiological and clinical scope. The aim is to highlight the existence of an androcentric culture calling for positive action measures to introduce gender mainstreaming in life. The ideological subjectivity that prevails when dealing with diseases such as fibromyalgia or migraine constitutes a proof of the sexist bias. This is further evidenced by the invisibility of women in health records of low frequency illnesses (designated “rare diseases”), despite the fact that in some of them the number of female cases is higher than that of men. We demonstrate this with the case of Familial Amyloidotic Polyneuropathy or Andrade's Syndrome, focusing on the town of Valverde del Camino in Huelva (Andalusia, Spain). In this fieldwork, we present the data from the identification of the objective needs regarding the morbidity records, showing that the number of women is smaller than the number of men and women have late cardiac complaints that appear with the beginning of the menopause, being the variability of the cardiac rate one of the first signs. This manifestation can lead to a late diagnosis and we know that an early diagnosis is preferred because of the progressivity and the irreversibility of the disease. The data obtained lead us to the conclusion that we must consider the gender as a key factor when we establish and apply the scientific knowledge.

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1. Introduction

In this work, we set out from the fact that the gender variable must be considered a key factor when establishing and applying knowledge. The systematic study of gender bias and adoption of the gender perspective in healthcare are still necessary and will provide data on the existence and characteristics of structural aspects of health systems, as well as biomedical, epidemiological, sociological research and training and their manifestations in daily clinical practice (Amo, 2008). It is necessary to forge a path towards a paradigm shift that allows the construction of a body of more precise and inclusive scientific knowledge, as well as a more just and egalitarian healthcare system (Tasa, Mora, & Raich, 2015).

The epistemological basis of the bias in healthcare involves a confluence of social, psychological and even historical factors. When discussing differences in the health of women and men, there are those who think (from an approach based upon Greek culture, in which the divine and the human are related) that men and women have divergent characteristics and behave differently due to biological determinants related to sex and gender. *“For the pre-Socratics, the biggest difference between the nature of men and women was the difference in heat of their bodies and the main empirical evidence to prove it was menstrual blood. Heat difference as the cause of sexual difference will be fundamental in Aristotle, taking for granted the greater fragility and weakness of women”* (Iglesias, 2002, p.17).

A group of academics and professionals from Africa, America, Asia and Europe (Ovseiko et al., 2016) maintain that assessing the impact of research sensitive to people’s needs from a gender perspective would be a determinant for political actions and scientific practice seeking equity between women and men.

However, the reality is that medical practice is often based on studies that show an absence and/or under-representation of women in their designs and their interpretations, as they are predominantly performed with male human or animal subjects (Tasa, Mora, & Raich, 2015). The male has always been the reference from which all humanity is generalised. There is no disaggregation of data by sex (Vázquez & Garrido, 2016; Ruiz Cantero, 2009) to be able to interpret the results and propose specific actions.

Another restriction entailed by this invisibility of women in studies is the insufficient incorporation of gender-related variables and categories of analysis (García Calvente, 2010). Social determinism, gender roles and stereotypes are overlooked, so the findings are not valid. Women and the feminine constitute a particularity and an addition, which limits the generalisation of the outcomes.

This has effects in practice, and Tasa, Mora, & Raich, (2015) qualified the provision of healthcare in an inappropriately different or similar way (due to erroneous data generalisation) to women and men as a manifestation of sexism in the health sector.

Evaluation of the impact of research is a multidisciplinary field, focused on optimising scientific, social and economic resources. This underpins the role that the University and educational/training institutions in general must play, eliminating the under-representation of women, both in participation and in the purpose and design of the works. This idea constitutes cornerstone of our professional performance as teachers and in research.

It is necessary to introduce training activities and research with gender perspective and sensitivity on social aspects, as well as in the biomedical, epidemiological and clinical areas (Ludwig et al., 2015; Ferrer Pérez & Bosch Fiol, 2005), and this is why we propose to carry out this work.

2. Problem Statement

We start from the premise that the determinants of health in the population are complex, such as income status, social class, social support networks, education, employment or working conditions. Likewise, social and physical environments, policies and health services. On a personal level, development from childhood, lifestyles, cultural, biological and genetic characteristics, as well as sex and gender, also intervene (Corral, Castaneda, Barzaga, & Santana, 2010).

Regarding the latter, Castañeda (2013) highlighted the roles of gender, stereotypes, level of education, occupation, use of time, sexual and reproductive health, and money management in the home or stages of the life cycle, among the factors that influence the health-disease process. These approaches present a vision of health in terms of social determinants with a gender focus that will contribute to the prevention of diseases, in addition to improving the quality and efficiency of health services (Castañeda, 2013). Not taking gender into account as an indicator means concealing the power relationships that pave the way to perpetuating discrimination and the absence of fair policies (Sen, George, & Östlin, 2005).

The differences in health between men and women are many. There is distinction by sex even in the perception of health status. Recent data show that in Spain men claim to feel better than women. Considering the population over 15 years old, 76.7% of men and 67.5% of women rated their health status as very good or good. In the 16 to 44 years' group, 94.6% of men and 91.1% of women perceived their state of health as "good" or "very good". In the group aged from 45 to 64, these percentages were 80.2% for men and 73.3% for women. And in the group aged 65 and over, the difference between men and women was even more pronounced (51.0% for men and 39.0% for women) (INE, 2017).

This perception may imply the need for medical care by women, which increases their life expectancy (Pérez, 2007). This may be the reason why the mortality rate is expected to reach 84.0 years in men and 88.7 years in women by the year 2029, which is a gain compared to the current values of 3.9 and 3.1 years, respectively (INE, 2017).

One current manifestation of gender bias in our environment is the case of the so-called "rare diseases". These diseases, although they are a minority, affect more than 3 million people in Spain and 27 million in Europe. This represents roughly 7% of the world population (FEDER, 2018). Some common features of these diseases are that they are low frequency (fewer than five cases per 10,000 inhabitants); their origin is unknown in most cases; they entail several health, social, psychological, educational and workplace issues; the epidemiological data on them are scarce; they pose difficulties in research due to the limited number of cases, and many of them lack effective treatments.

The fact that they have not been widely investigated even hinders their classification. The criterion habitually used to group them tends to be by their cause or the organ/part of the organism that may be affected. When a bibliographic search is carried out on this issue, the disease records found in the databases compile the information on people by age, country, symptoms or cause of death, among the most common. This is a determinant indicator and with a high incidence of gender bias, as health records are a very useful tool to approach and research all diseases (Salamanca & Aldana, 2012). The number of women affected, in some of the rare diseases and in certain populations, is higher than that of men (Lafurier, 2015; Valls, Fuentes, & Ojuel, 2008).

Table 01. Prevalence of rare diseases in men and women. Rate per 1000 inhabitants aged 6 and over (INE, 2017)

	BOTH GENDERS	MEN	WOMEN
TOTAL	89.70	72.60	106.34
RARE DISEASES	2.78	2.03	3.51

In medical sociology or health sociology, one step in the production of knowledge and demonstrating the sociocultural effects of gender bias on the quality of life consists of highlighting the need to identify them in order to seek positive action measures and introduce mainstreaming in today's society (Rey & Grande, 2017). This is one strategy of equality policies between women and men in the European Union (EU), which was made explicit in the Platform for Action of the Fourth World Conference on Women of the United Nations held in Beijing in 1995 (Bustelo & Lombardo, 2005).

The lack of research sensitive to gender phenomena helps perpetuate and legitimise the situation by omitting the predominant gender beliefs and attitudes in a sexist society such as ours (Kivlighan et al., 2015; Valls, Ojuel, López, & Fuentes, 2007). Contributing to the training of professionals is a crucial step towards overcoming this problem. With a view to potentiating these actions, we have conducted a study whose findings will guide our teaching and research work.

3. Research Questions

Are the chromosomal, anatomical and physiological differences sufficient to determine the formation and valuation of the concepts of man and woman, history different moments?

Does gender session still exist in science?

Are biological differences that determine the life, health, illness and death of people?

4. Purpose of the Study

The aim of this work is to demonstrate the dual gender bias suffered by women in health, and in particular those suffering from rare diseases. This study is part of an investigation (Montérdez, 2017) designed to draw a comparison of the social and health needs of patients with Familial Amyloidotic Polyneuropathy (FAP) Type I, between two of the most important foci worldwide: the area where one of the first manifestations of this disease occurred (Oporto, Portugal) and one of the two with the highest incidence found in Spain (Valverde del Camino, Huelva). Another objective of this to determine whether there is a difference in the rates and prevalence of the disease and the psychosocial needs among women and men who suffer from it.

FAP is an invalidating and lethal disease that affects the connective system, especially nerve cells and nerves that connect to organs (peripheral nervous system), leading to sensory, motor and autonomic neuropathy over the years. It is caused by the accumulation of a protein substance called amyloid. This unstable protein accumulates in the form of amyloid fibrils, causing an abnormal prealbumin, transthyretin (TTR), secreted by the liver, and normally responsible for the transport of substances such as thyroid hormone (thyroxine T4) and retinol. When it is deposited, it gives rise to a mixed neuropathy that manifests itself mostly after the fourth decade of life. The clinical signs are varied, initially with nervous and digestive

symptoms that progress slowly until death within a period of 10 years, unless subjected to Tafamidis treatment (recent intervention) or liver transplant (Munar, 2005; Esteban, Alós, Juan, & Olagorta, 2015). Please replace this text with context of your paper.

5. Research Methods

When we want to know about a certain social phenomenon such as the psychosocial and healthcare needs of people suffering from FAP, there are two ways to collect information: observation and questioning (Corbetta, 2007). In this study, both strategies used in several phases.

Each one of these phases can help us to identify the needs that the population that is suffering from this disease have. First, we want to get to know the objective needs, which is to say that we want to know the morbidity records. In order to do that, a documentary study has carried out, using a technique consisting of the selection and gathering of information of interest for the research. To this end, bibliographic searches were performed in databases including Scopus, IBZ Online, EBSCO, ERIC, DOAJ, DIALNET, JUFO and VIRTÀ, among others. In a second phase, interviews and discussion groups will be carried out with sick people, asymptomatic patients and relatives of the two study locations (Spain and Portugal) to get to know the needs of the affected population.

6. Findings

In this article we present the important data obtained in the phase I of this work. Among the information consulted there are works in which the study population characteristics are mentioned, but throughout the complete and detailed report there is no differentiation of symptoms or treatment according to gender. Results are interpreted based on studies of male models, without convincing evidence of their applicability to women (Hammarström, Härenstam, & Östlin, 2001). The consequences are that women's physiological processes are much less well-documented than men's, leading to poor healthcare, erroneous or late diagnoses, and undiagnosed symptoms due to their lack of credibility, among others (Sen, George, & Östlin, 2005; Eguiluz et al., 2011).

The initial findings from phase I show that women suffering from rare diseases suffer a twofold bias.

The health records found in the databases, which are a very useful tool to promote and investigate all diseases and especially those of low frequency (Salamanca & Aldana, 2012), compile information on people by age, country, symptoms or cause of death, among the most common, but not disaggregated by sex. This highlights the bias, as there are some works that do show how the way a disease affects women and men is one of the aspects that should be taken into account, since it is different. An example of this is the incidence of the sex of the person who inherits the mutation in FAP.

Even though we had focused in one locality, other carriers have been detected in other close localities such as Huelva, Beas, Niebla, Moguer and Nerva.

The first available information on this focus of FAP in Valverde del Camino dates back to 1999, when three people were diagnosed who died because they did not have a liver transplant. It was in the year 2000 when a man was transplanted for the first time (Montérdez, 2017).

It has been proved that the majority of the cases that have appeared in the locality of the study come from different families. This leads us to the conclusion that the number of asymptomatic carriers could be higher than 200.

From our fieldwork we have found that there are currently 137 people affected by Type I FAP in the focus of Huelva-Spain, of which there are 51 that have developed the disease and 86 asymptomatic carriers, in a population of 12,857 inhabitants of which 6,318 are men and 6,539 women (INE, 2016). The data show us that the number of men (71%) is higher than the number of women (29%). This is a proof that the Andrade's Syndrome affects unequally to women and men and that we require a gender approach towards this disease.

There are clinical manifestations that corroborate the need to consider the gender variable as a key factor when establishing and applying scientific knowledge. Proof of this is that women suffering from Type I FAP have later cardiac involvement, delayed until the onset of menopause (González López, 2015), when one of the first signs is the altered variability of the heart rate (Esteban et al., 2015).

This manifestation can lead to a later diagnosis when it is demonstrated that early intervention is important, as the disease is progressive and irreversible. Another proof of the need for early diagnosis is that liver transplant is a valid method for the treatment of Type I FAP and that the outcomes are better the younger the patients are.

In addition, another proof of the need of an early diagnosis in women is that the hepatic transplant is the only valid treatment for the Type I FAP and the results are better when the receptor of the transplant is young. The results of the phase I of our work show that when an early diagnosis has been made, the patients can have a normal life after the transplant. However, some of the patients could not walk and even died before they got their treatment.

7. Conclusion

With this work we have reached a double aim. On one hand we managed to raise awareness as the associations want, in order to help these sick people and their families. In this sense the educational activities are basic to diffusion for primary care medicine professionals and specialists- such as neurologists, cardiologists and internal medicine professionals- in order to do a proper diagnosis and derivate the patient to internal medicine to continue his study and treatment.

These manifestations, as an example of the treatment received by women and their health-related data, prompt us to act towards changing the vision of health, proposing health policies (actions) that address sex-gender, thereby furthering the optimisation of therapeutic (in particular) and social (in general) resources and healthcare in general, as well as the quality of life of all people.

In conclusion, we would like to point out some recommendations, such as promoting research on women, overcoming biological and sexist assumptions; improving healthcare information and record systems, establishing differentiation by sex; reviewing and identifying gender bias in the studies considered classic; dedicating public funds to carry out studies on women and strengthening initial and ongoing training plans, through the inclusion of content, methodologies and activities that allow reflection on the values, attitudes, stereotypes and gender roles present in professional practice.

The activities cited are just some examples of the many actions that can and should be carried out to create a space to share personal and collective experiences, acquire personal and social skills, and find alternatives to change the sexist consequences of gender roles.

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