

ably did not expect having to evaluate and analyse and that represents a decisive factor in the complexity of pathways of care. We wanted to explore this line of research because the “feminisation” of medical professions has become a matter of fact throughout the West and is changing the face of medicine. Today, the presence of female physicians is on the rise and they now outnumber men in almost all specialties, in a surprising way even in those fields which had a typically male connotation, such as the surgical branches. In this regard, we wanted to analyse this phenomenon by creating a series of absolutely innovative conferences titled “*La chirurgia al femminile: la medicina che cambia*” (Female surgery: changing medicine). The training objectives included the evaluation and impact of the presence of women in healthcare and the comparison with the male gender in order to identify which different relational dynamics come into play in the approach to care.

The interest in the implementation and dissemination of gender medicine is renewed and takes shape every year through new specific events that are also held to celebrate particularly significant dates such as the International Day for the Promotion and Health of Women, the World Day against Violence against Women and Women's Day.

Much has been done and will continue to be done, by committing the available resources to ensure that gender differences in healthcare are no longer a negative stereotype, but a real resource for the care for, and well-being of, all.

## References

- Baggio G. Dalla medicina di genere alla medicina genere-specifica. *IJGSM* 2015; 1: 3-5.
- Di Nuovo F, Onorati M, Nicola M, Cassoni M. Il valore aggiunto della differenza di genere nelle professioni sanitarie. *IJGSM* 2018; 4 (1): 34-6.
- Ministero della Salute (a cura di). Il genere come determinante di salute. Quaderni del Ministero Salute 2016; n. 26, aprile.
- Mori R. La medicina di genere nella programmazione socio-sanitaria. La Regione Emilia-Romagna c'è. *IJGSM* 2018; 4 (1): 36-8.
- Salmi M. La medicina genere-specifica nelle istituzioni italiane e europee. *IJGSM* 2017; 3 (2): 45-6.
- Signani F. La salute su misura. Medicina di genere non è medicina delle donne. Ferrara: Este Edition, 2013.
- Voltolini A. Inaugurato a Brescia un centro di documentazione e informazione sulla salute di genere. *IJGSM* 2017; 3 (2): 86-8.

## Multiple sclerosis: a project to get to know and tell the story of the people behind the disease

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In the field of neurodegenerative diseases, multiple sclerosis represents a paradigm of gender-specific medicine. Gender differences characterize, in fact, all aspects of the pathology, from its incidence to its clinical course, from prognosis to response to the different treatment options. If women are much more disadvantaged in terms of susceptibility (the ratio of women to men is 2 : 1 and the disease is increasing among women), on the other hand, among the female population benign forms prevail and any aggressive forms more frequently show a better clinical course, with the prevalence of inflammatory lesions rather than neurodegenerative ones showing on magnetic resonance imaging.

Clinical pictures and an expression of the progressive destruction of myelin sheaths used to transmit nerve impulses are characterized by wide variability in terms of neurological manifestations and progression. For most patients, the expression of the disease with the greatest impact is the limitation of movement due to muscle weakness, fatigue, poor coordination, rigidity and balance deficits, which generally evolve into conditions of persistent disability and increasing progression.

Multiple sclerosis does not reduce life expectancy compared to the general population, but has a significant impact on the quality of life of those affected and their loved ones. Moreover, the disease begins at a young age, generally between 20 and 40 years, and therefore in the most productive period of life, when personal and professional projects are taking shape.

The IO NON SCLERO project, developed by Biogen and Onda in col-

laboration with AISM (Italian Multiple Sclerosis Association) and under the patronage of SIN (Italian Society of Neurology), was born four years ago in Autumn 2014 with the aim of giving voice to people – patients and families – to reveal the authentic face of multiple sclerosis, telling the story of the disease through projects and testimonies of those who face it every day, with courage, optimism and determination. When the project was conceived, patients themselves, online, in blogs, forums and on social media, were referring to one another as *sclerati*: hence the title of the project, which was associated with the claim “stories of projects and dreams that do not stop with multiple sclerosis”.

The heart of the IO NON SCLERO community is a very active Facebook page: about 77,000 fans, 87% of whom are women; it is a real open space for sharing experiences, and there is also a website and an app containing general information about the disease and all the stories and testimonies collected over the years.

The project began with a web series, an online fiction divided into six episodes that put the spotlight on the disease, told in a simple and concrete way through the life of an ‘ordinary’ thirty-year-old woman who has to manage everyday life after receiving the diagnosis. The series, which was also the subject of an awareness campaign in cinemas, was awarded at the Rome Web Awards 2015.

The fiction was used to tell the story of real life, offering its commu-

nity of followers an online initiative focused on rewarding a project that aimed to improve the quality of life of patients and their families.

Some of the authors of the projects have become the protagonists of a real-life series, a journey around Italy in seven episodes. The stories have been gathered in a book in which the voice of patients and their families is joined by that of institutions and the scientific community.

In 2016, an online call to action called for the collection of video messages and photos, to give a face to the IO NON SCLERO community that in the meantime had grown and proved to be particularly active. 2017 was the decisive year for involvement and participation. An initiative was launched to share the story of turning points; the moment when people realized that multiple sclerosis would not prevail over their life plans. Matteo Caccia, storytelling expert and radio presenter, helped the IO NON SCLERO community to write their testimony through online video-tutorials. Among the more than 80 stories published on the site, 12 were chosen to be transformed into art tableaux starring in the travelling exhibition that toured six Italian hospitals and are included as illustrations in the IO NON SCLERO 2018 diary distributed for free in book shops.

The latest initiative born this year, ‘IL MIO GRAZIE’ (MY THANK YOU), invites patients to give ‘thanks’ to the people and things that are important for them to deal with the disease. From

the more than 200 messages that have been sent from the site and the app, 8 have been selected to be illustrated and will become an advertising campaign of billboards in different cities throughout Italy and adverts in newspapers and magazines with the aim of increasing awareness of this disease.

The sharing of stories and experiences is the engine that feeds the IO NON SCLERO community and women are the main drivers, in their dual role as people with multiple sclerosis and caregivers, with more than 83% participation in the various initiatives launched since 2016. This is not surprising: in general, women are more likely than men to use social media to share emotions and personal experiences.

IO NON SCLERO has opened a virtual space, which sometimes also becomes physical, where patients and caregivers can tell their stories and be encouraged by those of others who fight on the front line against multiple sclerosis, shifting the focus from disease to people.

The power of storytelling and sharing has proved extremely effective in telling the human side of the disease, well represented by stories of courage and great willingness to imagine a ‘rich’ life despite the diagnosis of a chronic disease such as multiple sclerosis. The experience of storytelling and sharing helps patients to elaborate their experiences of illness and give them meaning, processes that are fundamental to better address the course of treatment.

The project has been a great success thanks to patients and family members who share their life stories: positive testimonies that excite and leave their mark for everyone who is part of the rich world that is the IO NON SCLERO community.

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