

INSTAGRAM, THE TOOL OF E-PATIENTS WITH MULTIPLE SCLEROSIS

INSTAGRAM, LA HERRAMIENTA DE LOS E-PACIENTES CON ESCLEROSIS MÚLTIPLE

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Abstract: Every five minutes someone around the world is diagnosed with multiple sclerosis (MS). This autoimmune disease has no known cure and accounts for 55,000 patients in Spain, many of whom have become e-patient influencers on social networks, especially on Instagram (IG), sharing their experiences and promoting research. This paper studies the impact of Spanish e-patients with MS on IG. It adopts an initial descriptive and exploratory mixed approach, with the use of both quantitative and qualitative instruments: a survey of 224 participants and content analysis of the 10 MS instagrammers most mentioned by respondents. The results highlight that IG is the preferred social network for MS patients, who mainly consume content on advances in research and people's experiences, continuing to use their neurologist as a reliable source but not using the conventional media. It is therefore a valuable resource for managing MS, but digital literacy is indispensable to reach more patients. It offers the opportunity to optimise e-health, but there is still much work to be done.

Keywords: Digital literacy; E-patient; E-health; Multiple sclerosis; Instagram; Social media.

Resumen: Cada cinco minutos una persona es diagnosticada de esclerosis múltiple (EM.) en el mundo. Esta enfermedad autoinmune sin cura alcanza a 55.000 pacientes en España, donde muchos se han convertido en e-pacientes *influencers* en redes sociales (RRSS), especialmente en Instagram (IG), para visibilizar experiencias y promover la investigación. Este trabajo estudia el impacto de los e-pacientes españoles con EM en IG, desde un enfoque mixto descriptivo y exploratorio inicial, intercalando instrumentos cuanti-cualitativos: una encuesta con 224 participantes y el análisis de contenido de los 10 *instagrammers* de EM más mencionados por los encuestados. Así, destaca que IG es la red social preferida por los pacientes de EM, que consumen principalmente contenido sobre avances en investigación y testimonios, manteniendo a su neurólogo/a como fuente fiable, dejando a un lado a los medios de comunicación convencionales. Un recurso valioso para la gestión de la EM, donde la alfabetización digital es indispensable para llegar a más pacientes. Una oportunidad para optimizar la e-salud, donde aún queda mucho por trabajar.

Palabras clave: alfabetización digital; e-paciente; e-salud; esclerosis múltiple; Instagram; redes sociales.

1. Introduction

Social networking services (SNS) have positioned themselves as key tools for the visibility and normalisation of health issues and, specifically, in relation to diseases. The proliferation of campaigns, run by associations, and the publication of patients' experiences on their profiles have made the public more aware of and empathetic towards those suffering from illness. This is the case with multiple sclerosis (MS), the disease of a thousand faces, a neurodegenerative, autoimmune, demyelinating, multifactorial, inflammatory and chronic disease of the central nervous system that affects around 55,000 people in Spain and around 3 million people worldwide, according to the Spanish Society of Neurology (Sociedad Española de Neurología [SEN]) (Pérez, 2022). It is one of the leading causes of disability among young people in Spain, along with traffic accidents. People are usually diagnosed with it between the ages of 20-40.

Every year, there are 2,000 new MS diagnoses in Spain and the social media, more specifically, SNS, have become a key instrument for communication between patients and the dissemination of information about the disease. In this context, it is worth highlighting Instagram, where in recent years the presence of e-patients with MS, health instagrammers and influencers, has grown, creating a large community of active patients. However, to what extent is sharing information and experiences about MS beneficial? Is quality content about the disease being published? How does access to these publications affect other patients?

The main objective of this paper is to provide the scientific community with an in-depth analysis of this emerging profile of the health influencer, in this case the MS influencer, in the context of media influence, about which there have been few specific studies to date. It also aims to provide a perspective on the importance of the activity of these prosumers in the MS community, analysing what content is produced and consumed. To do this, MS patients have been consulted through an anonymous survey, which has allowed us to examine the most prominent instagrammer profiles.

Similarly, a quantitative-qualitative exploration of the content published by these e-patients has been carried out, identifying the benefits and risks of accessing this information, content of interest to the MS community and the level of Instagram's influence as a transmitter of knowledge about the disease. Consequently, the essential importance of digital literacy, ethics, rigour and netiquette in the dissemination of health information, and the importance of cross-checking data with reliable sources, have all been identified.

1.1. Multiple Sclerosis (MS) in Spain

The disease with a thousand faces. This is how MS is known, due to the heterogeneous nature of its symptoms and progression, ranging from partial loss of sight to reduced limb mobility, lack of balance and coordination, muscle stiffness (spasticity), slurred speech, sensory disturbances, cognitive impairment, incontinence, sexual dysfunction and fatigue (Fundación Esclerosis Múltiple [Multiple Sclerosis Foundation], 2022a). Its main cause is unknown and there is no cure, but it is believed to have a multifactorial, genetic and environmental, trigger where the hormonal factor, vitamin D deficiency, infection with the Epstein-Barr virus, smoking and microbiota are some of the agents whose coexistence is capable of altering the response of the immune system, allowing for the onset of the disease (Tessier, 2018).

Spanish neurobiologist Leyre Mestre explains that this disease combines three processes: autoimmunity, demyelination and neurodegeneration. The destruction of myelin is what triggers MS symptoms. This damage generates localised inflammation, which can be seen using Magnetic Resonance Imaging (MRI), and these are known as lesions that, over time, become internal scars. One symptom or another will be generated depending on where in the body this damaged axon is located (Guerrero, 2021).

In MS, early diagnosis and improved treatment options have managed to optimise the prognosis, as shown in the latest study on the social and health impact of MS in Spain, which has analysed the changes in patient perception over the last decade thanks to the participation of nearly 500 subjects from six Spanish hospitals. The data showed that more than 80 % of people diagnosed with MS are independent in terms of mobility and only 7 % use wheelchairs, which breaks the stigma attached to this disease (Sociedad Española de Neurología, 2019).

In fact, according to Esclerosis Múltiple España [Multiple Sclerosis Spain] (2021), there are more than fifteen treatments approved in Spain by the European Medicines Agency (EMA), classified as disease modifiers, which help to help control its progression, reduce the succession of outbreaks and lesions, as well as delay living with disability. According to Fundación Esclerosis Múltiple (2022b), three new treatments will soon be available and there are several others in clinical trial.

But medicines are not the only things responsible for making the prognosis of MS more bearable; it is also very important to complement them with healthy lifestyle habits, as Paula Rodríguez, neurologist at the Joan XXIII University Hospital, emphasises, including avoiding tobacco, alcohol, excess sugar and animal fats, as well as establishing a diet rich in fruit and vegetables and making physical activity a routine (Fundación Esclerosis Múltiple, 2022b).

This scenario, hand in hand with the digital revolution, has led many MS patients to empower themselves and share their experiences on SNS as a support network. They use the opportunity to urge the MS community to adopt these kinds of healthy habits and keep up to date with the disease, highlighting the importance of being active and working together on the path to finding a cure. These are the people who Ferguson (2007) conceptualised as e-patients. Fage-Butler and Nisbeth-Jensen (2016), for their part, point out that e-patients have replaced patients in the biomedical model, due to the role they play in the use of the Internet.

1.2. E-health and e-patient influencers in the new digital society

SNS are becoming one of the central axes of e-health, optimising the patient-professional relationship. In the words of García and Prieto (2022), e-health is the field of health integrated into the new information and communication technologies. It is in this new scenario, popularised by digital convergence, that e-patients emerge to form a new generation of informed health consumers who use the Internet to find out about a medical condition of interest to them. They can be family and friends, so are not necessarily the patients themselves (Ferguson, 2007). Thus, Traver-Salcedo and Fernández-Luque (2010) use this term to describe people who are prepared, trained, empowered and engaged in their health and in making decisions about their health care.

Langa (2021), meanwhile, adds that e-patients are becoming influencers in the field of health, providing the benefits of normalising, humanising, generating a 'mirror effect', raising awareness and disseminating information, promoting health, empowering, creating a community, encouraging research, promoting healthy lifestyles, advancing the optimisation of healthcare and enhancing psychosocial well-being. Toral Madariaga et al. (2013) describe this 'mirror effect' as an emotional synchronisation produced by the neurons of the same name, which favour the empathy and imitation promoted by social interaction.

However, there are also people who prefer not to make their illnesses public, who do not have access to the Internet or who do not use social media because of their age or socio-economic position, making digital literacy necessary to bridge a burning digital gap in access to and the use of information (Cruz Roja, 2021).

Another term that has become widespread in cyberspace is that of the prosumer. Toffler (1970) defines prosumers as those who generate goods, services or experiences and, at the same time, consume them. For their part, recent studies such as that of Arribas and Islas (2021) point out that the prosumer is

not only manifested in the creation of content, but also in the production process of a collaborative economy. Extrapolating this figure to e-health, e-patients are the prosumers par excellence, many of them health influencers. In this sense, González (2018: 47) defines influencers as the prosumers with the greatest impact on the audience, having the power to “influence them to adopt new products, services and even attitudes and behavioural patterns through their posts on social networks”. They do not have the legal power to prescribe medication, as they are generic, non-healthcare influencers, but they do promote healthy lifestyle habits among their followers (Jiménez-Marín et al., 2021).

A few years ago, patients were isolated, depending solely on the information provided by their doctor. However, now, with the resources provided by the web, they have become active, more informed and, therefore, more empowered patients (González, 2014). MS instagrammers are responsible for disseminating lifestyles while contributing to digital literacy. Social media and the Internet have helped to create a new source of knowledge, supporting the evolution of the healthcare system and optimising the relationship with patients thanks to technology (Traver-Salcedo and Fernández-Luque, 2011).

Fundación Telefónica (2022), through its annual report *'Sociedad Digital en España'* (Digital Society in Spain), analyses the rapid digital democratisation that we have experienced as a result of the pandemic, placing Spain at the forefront in Europe in terms of digital infrastructure, standing out in terms of connectivity and digital public services. More than 83 % of Spaniards use the Internet at least five days a week, with an increase in the number of elderly people who have started using the Internet en masse to keep in touch with their relatives.

Society has evolved thanks to the use of technology, but the digital divide is a reality that, while narrowing over time, is still present, especially among elderly and chronic patients, together with the absence of digital skills or the lack of availability of devices through which to access the Internet (Fundación Telefónica, 2022). In April 2022, figures indicated that 2.9 billion people in the world were still not using the Internet, 37 % of all the people on Earth. Even so, more than one in three users aged 16-64 surveyed by the Global Web Index (GWI) reported using the web to search for information on health issues (Kemp, 2022).

In view of the above, the importance of ethics in disseminating health information over the Internet must be taken into account, as pointed out by Castro (2018) and Ribas (2018), who advocate the responsible use of SNS, which is very much present in the application of netiquette, a kind of set of rules established by the users themselves to maintain a healthy environment for participating online. Using SNS to share how a disease is evolving has its risks, but

if it is done consciously and with the prudence it requires, great achievements can be made, from helping other people in the same situation to making the disease visible and raising awareness in society (Traver-Salcedo and Fernández-Luque, 2011).

1.3. Instagram: the social network for e-patients with MS

SNS connect people and entities with some kind of relationship or shared interests (Ponce, 2012). In the field of e-health, this medium has been used as a great communication tool, providing the response that patients often demand. Following the pandemic, the management of patient care through digital media is becoming one of the main channels (Fundación Telefónica, 2022). In fact, some medical centres shared Covid-19 prevention guidelines through Instagram, (Niknam et al., 2021) as well as recommendations for coping with the lockdown period (Silva et al., 2020).

Likewise, due to the increase in interest and consumption of information on certain diseases, Instagram has become a communication tool for e-patients and experts, the latter renamed by Pérez and Castro (2022) as micro-influencers, content creators who disseminate specialised information using visual resources and accessible language to reach a large number of followers. This phenomenon has increased since the pandemic began in 2020.

According to data analysed by Fundación Telefónica (2022), almost two thirds of Spanish users (64.7 %) consumed multimedia content in 2021, making it one of the main uses of the Internet. And the search for health-related information is one of the most common uses, with nearly 7 out of 10 Spaniards seeking information on the subject. Thanks to the use of hashtags, millions of people investigate the diseases they suffer from and connect with other patients and professionals, becoming prosumers and generating information based on their experiences (Gutiérrez and Tyner, 2012).

Instagram was launched in 2010 by Kevin Systrom and Mike Krieger (González, 2018) and according to Smith (2018), it is the most developed social network since its creation. Moreover, González (2018), supported by the research of Pittman and Reich (2016), underlines that image-based SNS make people feel less alone. An increasing number of individuals are encouraged to become e-patients, no longer having to cope with their disease alone, telling their story through this social network.

In terms of figures, in April 2022 Instagram had reached 1,452 million users worldwide, meaning that 23.4 % of all people over the age of 13 use it (Kemp, 2022). It is the preferred social network for Spanish users, where over 37 % use it to consume multimedia content, surpassing Facebook and TikTok

(Fundación Telefónica, 2022). According to the *Informe de Redes Sociales* (Social Networks Report) by IEBS Digital School (2022), despite the fact that Facebook has a greater number of registered users, over 61 % of Spaniards establish Instagram as their preferred social network for sharing their own content (Bello, 2022). This is also true for e-patients with MS.

However, as stated by Cambronero and Gómez (2021), it is essential to strengthen media and digital literacy in order to be able to make an intelligent selection of information. Likewise, media education has become a very interesting proposal in this field and media literacy is the protagonist. This is why as part of the process we need to prepare and train today's users with the relevant competences and skills (Elías-Zambrano, 2021). According to Funes (2018), MS is one of the diseases with the most information on the Internet, allowing patients to support each other and creating connections between its members, bringing together knowledge about MS in one place, raising awareness in society, normalising the disease, making the disease visible and promoting research.

However, in spite of these benefits, there are also risks. One of these is the vulnerability that comes with public exposure, and the problem caused by information overload, with misinformation also being possible. "According to the Digital News Report 2021, 67 % of Spanish users say they are concerned about disinformation and more than 60 % recognise having been exposed to hoaxes about the coronavirus" (Fundación Telefónica, 2022: 116). This is why it is so important to use reliable sources and check the data.

In this sense, it is worth noting that a new source of valuable information on MS in Spain was identified in May 2022, launched by one of the main resources. This is EMDATA, a repository on MS in Spain (Esclerosis Múltiple España, 2022), a pioneering initiative promoted by Esclerosis Múltiple España (EME) which was launched in response to the need to show the situation from the perspective of the patients, with the aim of sharing MS information collected through research, studies and surveys.

2. Methodology

The methodology used in this study is of a mixed quantitative-qualitative nature, combining survey and content analysis with the non-participant observation technique. This initial exploratory research aims to investigate the phenomenon of Spanish e-patients with MS on Instagram, analysing the content of their profiles and their impact on the patient community. In line with the objectives set forth in the introduction to this study, the theoretical hy-

pothesis is proposed that the presence of Spanish e-patients with MS on Instagram leads to the MS community being more informed and better able to manage their disease.

Firstly, documentation has been collected on the main terms or keywords: multiple sclerosis, e-patients, e-health, social networks, Instagram, influencers, instagrammers, using high-impact databases (Wos, Scopus, etc.), websites specialising in SNS and pages from MS patient associations.

The second step was to conduct a quantitative analysis of an exploratory-descriptive nature, using a survey. To do this, a 22-question questionnaire was generated in Google Forms, combining closed questions with multiple options and open-ended questions, in order to find out the opinion of the sample in a broader way. According to Quispe (2013), surveys are a way of obtaining data from a certain sample of people, which is very effective for diagnosing needs or evaluating the impact of actions or social phenomena, such as the repercussion of MS e-patients on Instagram on the MS patient community.

The study instrument has been validated by a group of experts in the field, achieving a high degree of internal consistency through Cronbach's Alpha, 0.879. Therefore, it can be confirmed that it is a reliable instrument to achieve the objectives of this research.

To collect data and determine the study sample, the instrument was launched via an informative poster on Instagram, Facebook and Twitter on 30 May 2022, coinciding with World MS Day, inviting Spanish MS patients to participate; directly to more than 60 social media profiles of associations and people with MS in Spain; and by email to 47 Spanish associations of MS patients, with a final collaboration of a total of 224 participants. The sample was selected by convenience sampling and, additionally, following the recommendation of Hernández et al. (2014), a duration of 15-20 minutes was calculated to reduce the likelihood of disinterest.

Based on Quispe (2013), who considers that it is inadvisable to use a survey as the only research instrument, we also incorporated content analysis through non-participant observation. In this way, according to Tejero-González (2021), the variables are not manipulated in the observational method. The aim is to measure, through observation, the conditions of a situation. Thanks to the survey, a ranking was obtained of the 10 Spanish MS Instagram profiles indicated by the participants, which has been used to analyse the content they publish about the disease during a season of daily use of this social network (1 January 2022 to 30 April 2022). In accordance with Stempel's constructed week technique, which allows a stratified sample to be drawn up by day of the week, this period was used, as May is MS month and, therefore, when there is most activity relating to the disease (Stempel and Westley, 1989).

In order to collect the main information from their profiles, an observation sheet was prepared, including eight parameters: a) real name of the instagrammer, b) name of the Instagram account, c) number of followers, d) number of posts, e) range of likes per post, f) frequency of content publication, g) subject of the posts and h) short biography (sheets available at <https://figshare.com/s/9921395acfee0c745377>).

In addition, it should be clarified that, based on Codina (2000: 41), who states that “an evaluation methodology must contemplate the option of including criteria for the inclusion/exclusion of resources, as well as a procedure for weighting the parameters”, after reviewing the most prominent profiles, @mariapombo was excluded from the analysis because she is an influencer with MS who is better known for her content on fashion trends than for reporting on the disease, about which she has posted only very occasionally. The decision was also made to exclude @unadecadamil, one of the first Spanish MS bloggers, who has not published content since the end of 2021. Finally, the sample consisted of a total of eight profiles, analysing a total of 235 posts over a period of four months.

To complete the analysis, a table was drawn up with eight evaluation criteria: authorship, creditworthiness, purpose, validity, rigour, relevance, design and objectivity; based on the proposals of Martínez (2016: 22) and Codina (2000). According to Codina (2000), authorship is one of the fundamental criteria for any content analysis. Martínez (2016) explains that it is a matter of knowing who is responsible for creating content; something that is supplemented by assessing creditworthiness, which consists of ensuring that the author has the appropriate training to handle the information offered (Codina, 2000). Purpose refers to identifying who the content is aimed at and what it is intended to achieve. Validity indicates whether the information is up to date and rigour is the criterion for evaluating whether what is published is correctly written, using appropriate language and justifying the sources. Relevance, on the other hand, refers to the pertinence and value of the content, while design reflects whether the publication has a meticulous, well-structured and innovative style. Finally, the objectivity item involves assessing whether the information published is persuasive in nature (Martínez, 2016).

In this table, each of these criteria has been scored from 0 to 2, where 0 corresponds to a poor application, 1 reflects an adequate execution and 2 an outstanding development. The weighted sum of the scores obtained has allowed us to order the ranking and develop the content analysis.

3. Analysis of results

3.1. Impact on MS patients

The initial sample for this study consisted of 224 Spanish individuals with MS who were asked to share their opinions on how the activity of MS e-patients on Instagram impacts their lives. They are the first sample in this study. Their ages range from 21 to 69 years old, with 80 % being women. Participants are from various autonomous communities, with notable representation from Madrid (50), Cáceres (29), Barcelona (22), and Seville (17) (Figure 1). All of them share the same disease, but not the same activity on SNS, so it was interesting to understand the perspective of both e-patients and patients who are beginners in the field of social media.

Figure 1: Map of participants in the e-patients Instagram MS survey by province

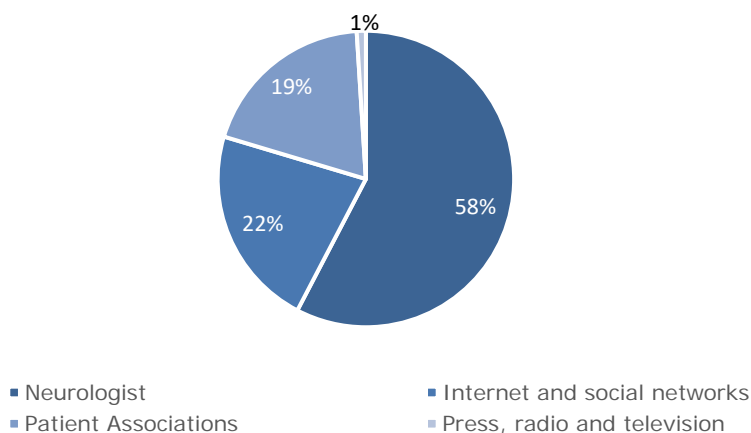


Source: own research with paintmaps.com using data from the MS patient survey on Google Forms.

Most participants fall within the age range of 29 and 50 years old (74.3 %), with the highest percentage (5.3 %) being 13 MS patients aged 33, as well as 27 patients diagnosed in 2021. The high participation of young, recently diagnosed patients, combined with the age of detection usually being around 30 years old, increases the likelihood that they are digitally literate and therefore familiar with the use of the Internet and SNS.

Among the 224 respondents, 129 patients (58 %) indicated their neurologist as the best source of MS information (Figure 2). Another 50 preferred using the Internet and social media, and more than 19 % highlighted patient associations as the best source of information on MS. In any case, almost 85 % state that they check the information with their neurologist or other reliable source, indicating a high degree of responsibility and demand for information about their disease. It is noteworthy that there is almost no mention of the conventional media, something that seems to be linked to the lack of accuracy and the publication of misleading headlines, for example with the Epstein-Barr virus (EBV), also known as mononucleosis, at the beginning of 2022.

Figure 2. Best source of information on MS according to patients



Source: own research with results from the MS patient survey on Google Forms.

However, it should not be forgotten that many newly diagnosed MS patients have reported that they use the Internet as their main source (29 %), pushing information received at their hospital into second place. Around 24 % combined different sources to learn more about MS, while 11% (18 patients) preferred not to search about their condition.

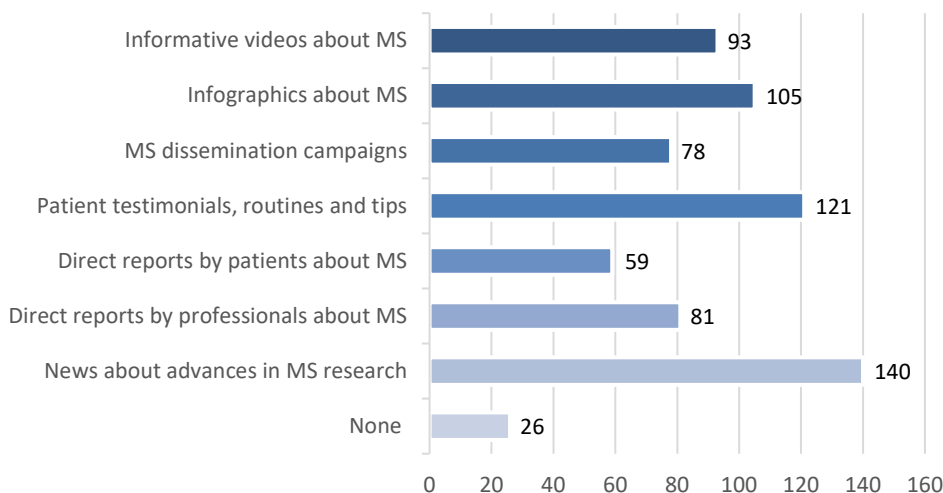
In terms of the use of SNS, 212 respondents confirmed having a profile on a social network; Instagram (85 %), Facebook (83 %), Twitter (36 %) or TikTok (16.8 %), with Instagram being preferred by MS patients, accounting for 58 % compared to the others. However, around 10 % of respondents said they do not know how to use it but would like to learn how to. The next most used social network is Facebook, selected by 27.9 % of the survey participants. In addition, 160 of the 224 respondents report that they follow similar profiles because it helps them to cope with their disease and they feel that they can help

each other. In contrast, 28 % of them do not follow these instagrammers because they do not use this social network, they prefer to follow patient associations or they do not like hearing about the experiences of other people with MS. In general, however, most of the respondents consider that the presence of e-patients with MS on Instagram is beneficial, especially for increasing the visibility of the disease and to provide the opportunity to meet other people in the same situation.

However, some patients show a certain reluctance. The main objection is the huge empathy that can be generated by learning about the experiences of others, as well as the risk of generalizing, as it is a disease that affects each person in a different way. They also highlight the lack of accuracy in the information, which can lead to the dissemination of false information (12 %). Some participants expressed the fear that the disease could be downplayed and trivialised (9 %), while others were concerned that communication on SNS might lead to a stigmatisation of MS.

Overall, the type of content that most interests MS patients on Instagram, as shown in Figure 3, is about advances in research, as reported by more than 64 % of respondents (140 participants), as well as testimonials, routines and tips from e-patients with MS, information in which 54 % of participants expressed an interest. In contrast, the least significant content relates to direct reports from patients about MS, according to 26 %, or 59 of the participants.

Figure 3. Content consumed by MS patients on Instagram

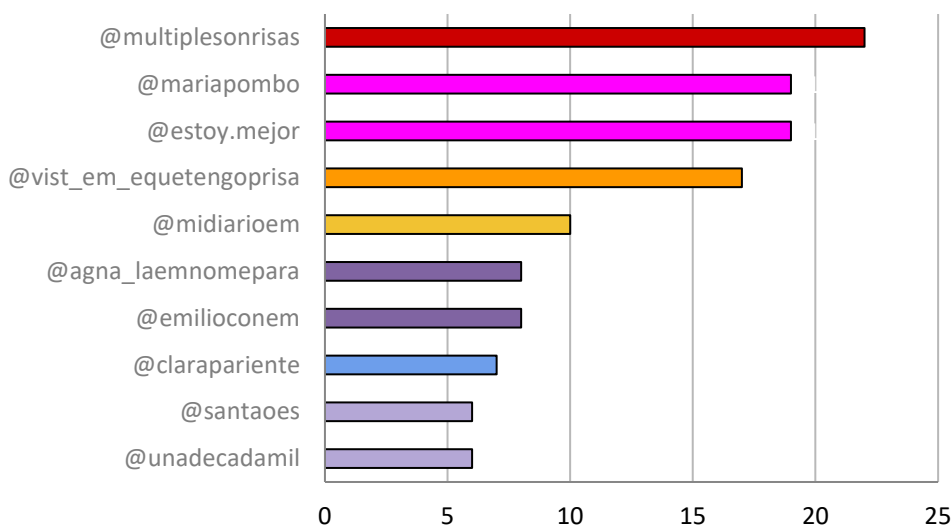


Source: own research with results from the MS patient survey on Google Forms.

3.2. Influencers and e-patients

In addition, 235 publications were analysed over four months using the ranking (Figure 4) and non-participant observation, with the support of the sheets. This revealed that the publication frequency for Spanish MS influencers on Instagram is on average seven posts per e-patient per month, which means that most MS instagrammers leave periods of four days without updating their feeds. And the most published content includes dietary guidelines, recommendations around exercise, charity campaigns, humour and personal experiences, with these latter having more impact, along with advances in MS research.

Figure 4. Ranking of the 10 most mentioned MS instagrammers



Source: own research with results from the MS patient survey on Google Forms.

It should be noted that no relationship has been observed between the number of posts and the number of likes, concluding that quantity is not synonymous with quality. Instead, it has been observed that creativity is rewarded, as in the case of @emilioconem's humorous cartoons, as is content that arouses positive empathy in response to achievements, such as @santaoes's publication that obtained the most "likes" in the phase analysed, in which he returned to basketball after a long period away from the sport for health reasons. Content seen as having commercial aims is penalised, such as the post by @estoy.mejor with the fewest likes, a live broadcast in which she tries to persuade users to sign up for a mindfulness course that she is teaching.

Thanks to Table 1, we have been able to analyse the content in more detail, observing that Spanish MS instagrammers tend to use their profiles to recount their experiences of living with the disease, such as the effects of an outbreak or changes in treatment, a type of content that is purely subjective in nature. But they also share general informative content about MS, such as the range of possible symptoms or factors influencing the diagnosis, which makes the content balanced with objectivity.

Table 1. Items for analysing IG MS content

IG PROFILES/INDICATORS	Authorship	Creditworthiness	Purpose	Validity	Rigour	Relevance	Design	Objectivity	TOTAL	AVERAGE
@vist_em_equetengoprisa	2	2	2	2	2	2	2	1	15	1,875
@emilioconem	2	2	2	2	2	2	2	1	15	1,875
@santaoes	2	2	2	2	2	2	2	1	15	1,875
@multiplesonrisas	2	2	2	2	1	2	1	1	13	1,625
@clarapariete	2	2	2	2	1	1	1	1	12	1,5
@estoy.mejor	1	1	2	2	1	2	2	0	11	1,375
@midiaroem	1	1	2	2	1	1	1	2	11	1,375
@agna_laemnomepara	1	1	2	2	1	1	1	1	10	1,25

Source: own research.

If we look at creditworthiness and authorship, in terms of whether Spanish MS instagrammers have enough training to share the information they offer, this is not found for the two profiles @estoy.mejor and @agna_laemnomepara, who frequently share information that should be handled by experts. The other accounts analysed were considered to be fairly balanced, as they shared more prudent content.

In general, all eight profiles fulfil their purpose and validity, as they identify their target audience, mainly MS patients, very well and publish up-to-date information, showing that Spanish MS influencers are up to date. However, of all the profiles analysed, @vist_em_equetengoprisa, @santaoes and @emilioconem stand out in terms of rigour and design, due to the correct drafting of their posts and the originality of their approach to MS.

4. Discussion and conclusions

The aim of this study is to identify how communication in MS is developing around the emerging phenomenon of e-patients on Instagram, present an overview of this situation and provide the scientific community with an in-depth analysis of this health influencer profile.

The main question revolves around what type of content MS instagrammers publish and to what extent the type of information they generate is positive for the patient community. Langa (2021) listed a number of benefits, which coincide with those set out by Funes (2018), derived from the dissemination of knowledge about the disease in order to humanise, normalise and generate empathy; all of them, as has been shown, are fulfilled by Spanish MS influencers, whose personal experiences are the quintessential content on their profiles. These testimonials are responsible for generating the 'mirror effect', which Langa (2021) and Traver-Salcedo and Fernández-Luque (2010) define as the need of human beings, social beings, to feel reflected in others.

It should be noted that this scenario is aided by SNS, especially Instagram, where the power of images and e-patient stories generates connections through emotions, enhancing psychosocial well-being, as suggested by Pittman and Reich (2016), reducing feelings of loneliness and creating a supportive community, as @clarapaciente does, along with @midiaríoem, who shares stories about different e-patients together with her own in order to show what it is like to have MS.

Likewise, the role of these prosumers as health influencers has been corroborated, sharing healthy lifestyle habits, focusing on exercise, such as @agna_laemnomepara and @estoy.mejor; or on food, such as @vist_em_equetengoprisa through her anti-inflammatory meals. There are also profiles such as @santaoes, which provide benefits through charity projects, promoting campaigns to encourage research into MS. No less important is the role of @multiplesonrisas and @emilioconem, who show what it is like to live with MS through a touch of humour and sarcasm, demanding that patients have a voice and that healthcare needs to be optimised, bringing to light the sector's shortcomings.

In view of the above, it can be argued that in relation to e-health, e-patients are the prosumers and influencers par excellence. Ferguson (2007) observed that many patients were not satisfied with the diagnosis and went further, taking the initiative and becoming, on many occasions, clinical researchers. This has been confirmed through the survey, in which more than 88 % of MS patients reported that they like to keep up to date with advances in research into their disease; and through the non-participant observation of MS instagrammers, where the profile of an empowered e-patient with initiative stands

out. One example is @vist_em_equetengoprisa, who decided to train in nutrition and psychoneuroimmunology (PNI) in order to gain skills to improve her quality of life with the disease.

As highlighted by González (2014), online resources help patients to be better informed and, therefore, have more decision-making capacity. However, as Llordachs (2017) pointed out, there are risks arising from the enormous amount of information available in cyberspace. For this reason, in order to avoid searches that return misleading results, it is essential to know where to look, with a good resource being patient associations, where, as Arantón (2009) suggests, verified information is published, as well as talking to health professionals.

Despite e-patient content having become a fundamental support resource for the MS community, the neurologists continue to be the main source for verifying information, while patients rarely turn to conventional media. In this context, Romero et al. (2016) and Cambronero and Gómez (2021) argue that there is a need to strengthen media and digital literacy in order to acquire the necessary skills for the responsible consumption and critical selection of information, which is essential for the democratisation of society.

This study confirms the power of Instagram as a social influence tool, positioning it as the main social network for MS patients. It serves to illustrate a more hopeful side to the idea of the overall prognosis for this disease, without hiding the harshness of relapses or deterioration. Even so, MS patients are aware of the danger of feeling excessive empathy and making comparisons, as SNS are spaces where shared emotions generate a kind of large-scale emotional contagion, as highlighted by Serrano (2016), so it must be borne in mind that this is the disease of a thousand faces and that each case is different.

To conclude, it can be said that most posts by Spanish MS instagrammers have a positive impact on the patient community, serving as a support group throughout the course of the disease. Moreover, people with MS are cautious about the content they consume, with news about scientific advances and personal experiences dominating, verifying the information and avoiding trivialisation or stigmatisation. In this sense, we can emphasise the need for digital literacy, to educate people in digital skills and make this tool accessible to more patients. Likewise, e-patients with a presence on social media need to take into account the netiquette, ensuring a healthy digital environment, together with rigour and caution in their posts.

This panorama provides the opportunity for future lines of research with more in-depth studies that support the optimisation of e-health. This includes an expansion of the sample, as well as comparative analyses through which the impact of MS instagrammers in different geographical areas can be assessed,

along with the communication trends of e-patients with other diseases. All of this is with the additional aim of contributing to creating critical users and members of the public who are able to inform themselves about their own health and that of their loved ones via the Internet.

References

- ARANTÓN, L. (2009). Asociaciones de pacientes. *Enfermería dermatológica*, 3(6), 36–38.
- ARRIBAS, A., & ISLAS, O. (2021). El prosumidor en la economía colaborativa: nueva manera de participar en el mercado de consumo. *Palabra Clave*, 24(2), 1-22. doi.org/10.5294/pacla.2021.24.2.7
- BELLO, E. (2022). Instagram destrona a Facebook como la red social más utilizada por los. *Thinking for Innovation*. <https://bit.ly/3aGscGN>
- CAMBRONERO, B. & GÓMEZ, B. (2021). El uso de redes sociales y su implicación para la comunicación en salud. Revisión bibliográfica sobre el uso de Twitter y la enfermedad del cáncer. *Doxa Comunicación. Revista Interdisciplinaria de Estudios de Comunicación y Ciencias Sociales* (33), 377–392. doi.org/10.31921/doxacom.n33a868
- CASTRO, M. [TEDx Talks] (29, marzo, 2018). *El universo NETiqueta: personas, comunicación y emociones* [Video]. Youtube. <https://bit.ly/3SDYHVC>
- CODINA, LL. (2000). Evaluación de recursos digitales en línea: conceptos, indicadores y métodos. *Revista española de Documentación Científica*, 23(1), 9–44. doi.org/10.3989/redc.2000.v23.i1.315
- CRUZ ROJA (s.f.). Qué es la brecha digital y cómo evitar que provoque desigualdad. <https://bit.ly/3NbO81C>
- ELÍAS-ZAMBRANO, R. (2021). El modelo educomunicativo en el contexto del nuevo marketing digital. *Reflexiones en torno a la comunicación organizacional, la publicidad y el audiovisual desde una perspectiva multidisciplinaria* (pp. 193-204). Fragua.
- ESCLEROSIS MÚLTIPLE ESPAÑA (2021). Tratamientos Esclerosis Múltiple. <https://bit.ly/3gJP8aE>
- ESCLEROSIS MÚLTIPLE ESPAÑA (2022, 5 de mayo). La persona con Esclerosis Múltiple, en el centro. <https://bit.ly/3sxjRdv>
- FAGE-BUTLER, A. M., & NISBETH JENSEN, M. (2016). Medical terminology in online patient–patient communication: evidence of high health literacy? *Health expectations*, 19(3), 643-653. doi.org/10.1111/hex.12395
- FERGUSON, T. (2007). E-patients: How they can help us heal healthcare. *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care*, 93-150.

- FUNDACIÓN ESCLEROSIS MÚLTIPLE (2022a). Síntomas de la Esclerosis Múltiple. <https://bit.ly/2HDPPHw>
- FUNDACIÓN ESCLEROSIS MÚLTIPLE (2022b). Tratamientos en Esclerosis Múltiple. <https://bit.ly/3WthkOq>
- FUNDACIÓN TELEFÓNICA (2022, 9 de marzo). Sociedad Digital en España 2022. Informes SIE. <https://bit.ly/3sxDdQO>
- FUNES, C. (2018, 15 de noviembre). Redes sociales y esclerosis múltiple. AEDEM-COCEMFE. <https://bit.ly/3UOHQOe>
- GARCÍA, R. M. & PRIETO, M. S. (2022). Uso de redes sociales en comunicación sanitaria. *Formación Médica Continuada en Atención Primaria*, 29(3), 18–27. doi.org/10.1016/j.fmc.2022.03.003
- GONZÁLEZ, E. L. (2018). Instagramers, la competencia mediática en los prosumidores emergentes. [Tesis de maestría, Universidad Internacional de Andalucía y Universidad de Huelva] Retrieved from <https://bit.ly/3N95wgP>
- GONZÁLEZ, A. (2014). La autonomía del paciente con enfermedades crónicas: De paciente pasivo a paciente activo. *Enfermería Clínica*, 24(1), 67–73. doi.org/10.1016/j.enfcli.2013.11.005
- GUERRERO, C. [CSIC Divulga] (4, agosto, 2021). La esclerosis múltiple, con Leyre Mestre. Ciencia para leer [Podcast]. iVoox. <https://bit.ly/3FiiVkr>
- GUTIÉRREZ, A. & TYNER, K. (2012). Media Education, Media Literacy and Digital Competence. *Comunicar*, 19(38), 31–39. doi.org/10.3916/C38-2012-02-03
- HERNÁNDEZ, R., FERNÁNDEZ, C. & BAPTISTA, P. (2014). *Metodología de la investigación*. McGraw-Hill Interamericana.
- IEBS DIGITAL SCHOOL (2022). Informe Redes Sociales 2022. IEBS. <https://bit.ly/3f562zW>
- JIMÉNEZ-MARÍN, G., BELLIDO-PÉREZ, E., & TRUJILLO SÁNCHEZ, M. (2021). Publicidad en Instagram y riesgos para la salud pública: el influencer no sanitario como prescriptor de medicamentos, a propósito de un caso. *Revista Española de Comunicación en Salud*, 12 (1), 43-57.
- KEMP, S. (2022, , 21 april). More than 5 billion people now use the internet. *We Are Social UK*. <https://bit.ly/3NbPIQa>
- LANGA, C. (2021, 10 de febrero). Los Epacientes, pacientes influencers en el ámbito de la salud. *Cícero Comunicación*. <https://bit.ly/3zhxzVD>
- LLORDACHS, F. [HEALTHIO 2017] (9, diciembre, 2017). *E-Pacientes, los tiempos cambian para todos* [Vídeo]. Youtube <https://bit.ly/3DyIvlu>
- MARTÍNEZ, L. J. (2016). Cómo buscar y usar información científica: Guías para estudiantes universitarios 2016. *Universidad de Cantabria*. <https://bit.ly/3V6WdR4>

- NIKNAM, F., SAMADBEIK, M., FATEHI, F., SHIRDEL, M., REZAZADEH, M. & BASTANI, P., (2021). COVID-19 on Instagram: A content analysis of selected accounts. *Health Policy and Technology*, 10(1), 165-173.
doi.org/10.1016/j.hlpt.2020.10.016
- PÉREZ, A. (2022, 30 de mayo). En España se diagnostican ya más de 2.000 nuevos casos de esclerosis múltiple al año. *Sociedad Española de Neurología*.
https://bit.ly/3Fg1Hon
- PÉREZ, C., & CASTRO, A. (2022). Creadores de contenido especializado en salud en redes sociales. Los micro influencers en Instagram. *Revista de Comunicación y Salud*, 13, 23–38. **doi.org/10.35669/rcys.2023.13.e311**
- PITTMAN, M. & REICH, B. (2016). Social media and loneliness: Why an Instagram picture may be worth more than a thousand Twitter words. *Computers in Human Behavior*, 62, 155–167.
doi.org/10.1016/j.chb.2016.03.084
- PONCE, I. (2012, 17 de abril). MONOGRÁFICO: Redes Sociales (Social Media). *Observatorio Tecnológico del Ministerio de Educación, Cultura y Deporte*.
https://bit.ly/3f4Qz34
- QUISPE, A., (2013). *El uso de la encuesta en ciencias sociales*. Ediciones Díaz de Santos.
- RIBAS, E., (2018, 3 diciembre). Qué son las Netiquetas y cómo seguir las reglas básicas en Internet. *Thinking for Innovation*. **https://bit.ly/2IATG33**
- ROMERO, L., TORRES, Á., PÉREZ, M. A. & AGUADED, I. (2016). Analfanautas y la cuarta pantalla: ausencia de infodietas y de competencias mediáticas e informaciones en jóvenes universitarios latinoamericanos. *Fonseca, Journal of Communication*, 12(12), 11. **/doi.org/10.14201/fjc2016121125**
- SOCIEDAD ESPAÑOLA DE NEUROLOGÍA (2019, 18 de diciembre). La esclerosis múltiple afecta ya a más de 50.000 personas en España.
https://bit.ly/3W1S2Yu
- SERRANO, J. (2016). Internet and emotions: New trends in an emerging field of research. *Comunicar*, 24(46), 19–26.
doi.org/10.3916/C46-2016-02
- SILVA, A. G., BATISTA, T., GIRAUD, F., GIRAUD, A., PINTO, F., BARRAL, J., GUIMARÃES, J. N. & RUMJANEK, V. (2020). Science communication for the deaf in the pandemic period: absences and pursuit of information. *Journal of Science Communication*, 19(5), 1-19. **doi.org/10.22323/2.19050205**
- SMITH, S. (2018). Instagram abroad: performance, consumption and colonial narrative in tourism. *Postcolonial Studies*, 21(2), 172–191.
doi.org/10.1080/13688790.2018.1461173
- STEMPEL, G., & WESTLEY, B. (1989). *Research methos in mass communication*. Prentice Hall.

- TEJERO-GONZÁLEZ, J.M. (2021). *Técnicas de investigación cualitativa en los ámbitos sanitario y sociosanitario*. UCLM.
- TESSIER, E. (2018). Relación entre la Microbiota Intestinal y los Procesos Neurodegenerativos. Esclerosis Múltiple. [Tesis de maestría, Universidad Complutense de Madrid]. <https://bit.ly/3RngWzp>
- TOFFLER, A. (1970). *Future shock*. Bantman.
- TORAL MADARIAGA, G., GARCÍA URETA, I., & MURELAJA IBARRA, J. (2013). La preparación de comunicadores Resonantes. De las redes neuronales a la sociedad red. Teoría de la Educación. *Educación y Cultura en la Sociedad de la Información*, 14 (1), 228-247.
- TRAVER-SALCEDO, V., & FERNÁNDEZ-LUQUE, L. (2010). El ePaciente y las redes sociales. *Itaca*. <https://bit.ly/3Pf1LGt>
- TRAVER-SALCEDO, V., & FERNÁNDEZ-LUQUE, L. [Sabien UPV]. (8, julio, 2011). *Presentación del libro "El epaciente y las redes sociales"* [Vídeo]. Youtube. <https://bit.ly/3yPdrsW>