Self-Esteem in the Making: Young Influencers with Rare Diseases on Instagram

Autoestima en construcción: jóvenes influencers con enfermedades raras en Instagram

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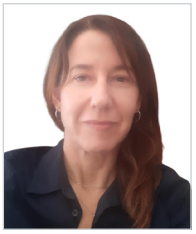

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Abstract:

The increasing visibility of rare diseases (RDs) on social media has been made possible, in part, thanks to the active involvement of those affected-especially the younger ones. The aim of this research is to understand the motivations and expectations of people living with a rare disease when creating a personal profile where they share information about their condition and daily life, as well as the impact that this public exposure has on their self-esteem and emotional well-being. To this end, ten semi-structured interviews were conducted with young people living with rare diseases who have prominent Instagram profiles. The results show that their main motivations are to participate in the social discourse on these conditions from a first-person perspective and to provide straightforward information based on their own experiences. The main emotional benefit is the sense of usefulness, since their shared information helps others who may be going through similar situations and this, in turn, boosts their self-esteem and enables them to build a community and network. Their main source of dissatisfaction is having to deal with negative comments that sometimes can affect their emotional balance.

Keywords:

Rare diseases; emotional health; digital empowerment; digital risks; influencers.

Resumen:

La progresiva visibilización de las enfermedades raras (ER) en las redes sociales ha sido posible, en parte, gracias a la participación de las personas afectadas, especialmente las más jóvenes. El objetivo de esta investigación es conocer las motivaciones y expectativas de las personas con una enfermedad rara a la hora de crear un perfil personal en el que aportan información sobre su enfermedad y su vida cotidiana, así como las consecuencias que esta exposición pública les acarrea para su autoestima y bienestar emocional. Con este fin se han realizado diez entrevistas semiestructuradas a jóvenes con enfermedades raras y con perfiles destacados de Instagram. Los resultados indican que sus principales motivaciones son participar en el debate social sobre estas enfermedades en primera persona y ofrecer información de forma sencilla, a partir de su propia experiencia. El principal beneficio emocional es el de sentirse útiles porque su información ayuda a otros que pueden estar pasando por lo mismo y eso les permite mejorar su autoestima, así como crear una comunidad y red de contactos. La principal insatisfacción es tener que lidiar con los comentarios negativos que en ocasiones pueden afectar a su equilibrio emocional.

Palabras clave:

Enfermedades raras; salud emocional; empoderamiento digital; riesgos digitales; influencers.

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1. Introduction

Rare diseases (RDs), also known as minority diseases (MDs) or low-prevalence diseases (LPDs), are those with a prevalence of fewer than one case per 2,000 inhabitants. Most are congenital and involve some degree of disability –sometimes very severe– and it is estimated that they affect between 6% and 8% of the European population (Wakap *et al.*, 2020). From a social standpoint, these diseases pose a paradox: while each one affects "very few" people, taken together, they represent a significant public health issue for a substantial proportion of citizens. This is even more evident if we consider not only those directly affected but also their families, who share in the challenges and suffering associated with the illness. In Spain, for example, it is estimated that around three million people live with an RD, a figure that increases considerably when those who live with or care for them are included (Vicente *et al.*, 2021).

The minority –or rather, marginalised– status of RDs has meant that for decades, biomedical research into them was almost negligible. Although interest in understanding these conditions from a biomedical perspective has grown in recent years, with major advances in genetics and molecular biology, significant economic, clinical and methodological barriers remain in

addressing their aetiology, diagnosis and treatment (Páramo-Rodríguez *et al.*, 2023). Although interest in understanding these conditions from a biomedical perspective has grown in recent years, with major advances in genetics and molecular biology, significant economic, clinical, and methodological barriers remain in addressing their aetiology, diagnosis and treatment (Páramo-Rodríguez *et al.*, 2023).

Equally limited has been the attention paid by the social sciences to the circumstances of people with rare diseases: their social and healthcare needs, their difficulties in accessing treatment, and the many challenges –psychological and emotional, occupational, economic, and others– that living with such conditions entails, both for the individuals affected and for their families. In Spain, this lack of attention has begun to be addressed over the past few decades through social research projects such as the ENSERio studies (Díaz & Huete, 2009; Solves *et al.*, 2018).

This gradual, though still modest, increase in interest –both in the biomedical and social sciences– has developed alongside a growing social movement that has strengthened since the creation of the Spanish Federation of Rare Diseases (FEDER) in 1999. Over the past twenty years, this has also been reflected in approaches to the communication of rare diseases, particularly through discourse analysis (Bañón, 2007a, 2007b; Ridao, 2012) and content analysis (Sánchez-Castillo, 2013; Sánchez-Castillo & Mercado-Sáez, 2014), which have contributed significantly to understanding how the media represent these conditions (Solves & Sapiña, 2024).

Most of these studies have focused on the image constructed and disseminated of RDs –especially by the leading social agents involved in shaping public discourse: traditional media (Arcos-Urrutia, 2024), patient associations (López-Villafranca & Castillo-Esparcia, 2017), and political institutions (Asencio-Ibáñez, 2022). Only recently has attention turned to the need to understand the discourse produced and circulated through new media, as social media have demonstrated their potential to raise visibility and combat the stigmatisation of people with disabilities (Bonilla-del-Río *et al.*, 2022).

1.1. Rare Diseases and the Internet

The relationship between the Internet and rare diseases has thus become a relevant factor for those interested in the dissemination of information about health and illness, as well as for the activities carried out by patient groups and even by individual patients when seeking information online (Ashtari & Taylor, 2022; Tozzi *et al.*, 2013). Moreover, the Internet has facilitated the development of exemplary and authoritative health information platforms, such as the Orphanet portal (Nabarette, 2003), whose value is heightened given the difficulties that exist in gathering, organising and disseminating information about these conditions (Dagiral & Peerbaye, 2010; Pauer *et al.*, 2017). It is therefore one of the most dynamic lines of research both internationally and, more recently, within the Spanish context.

Traditional institutional discourses about rare diseases persist in mainstream media, albeit with attempts to adapt to this new communicative landscape. Meanwhile, social media have become the arena where new forms of mass communication emerge and proliferate –narratives that question and subvert those traditional discourses. Now, difference, individuality, even eccentricity –everything that was once rendered invisible for being considered outside the norm– flourishes with unrestrained

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force in these digital spaces, establishing itself, in fact, as a new way of presenting and understanding who we are (Sánchez-Castillo & Mercado-Sáez, 2021).

As a result, the inadequate representation of people with rare diseases in society –so often analysed and denounced in academic literature in recent years– has begun to shift thanks to the rise of social media. These new communication platforms already count over five billion active users worldwide, 39 million of them in Spain. In terms of applications, most users prefer Instagram, which in 2024 became the world's most popular social network, surpassing WhatsApp, Facebook, and TikTok (We Are Social & Meltwater, 2025).

Consequently, this paradigm shift is compelling scholars to pay attention to the new discourses and narratives being developed on social media, since these are where the focus of attention lies for both new and not-so-new generations. Although some studies have already explored the discourse and content shared by people with rare diseases on these platforms (Castillo-Esparcia *et al.*, 2015; López-Villafranca, 2020), none have yet examined the motivations and expectations that drive individuals with rare conditions to expose themselves and participate in social networks. For this reason, the present study focuses on this more empowered and resilient form of discourse, which is transforming both the social image of rare diseases and our collective understanding of what it means to live with one.

1.2. Users, Prosumers and Influencers

This new communication paradigm, in which social networks offer infinite possibilities for participation through the sharing of stories, opinions and audiovisual content, transforms the user into what is known as a *prosumer*. The term, coined by sociologist Alvin Toffler in 1979, merges the notions of producer and consumer (González-Reyes, 2021), encapsulating the evolution of audiences into multitasking individuals who not only consume content but also comment on it, express opinions, rate other users, and even create their own material. This shift from passive to active individual has been driven by technological advances and the proliferation of digital devices, which have altered patterns of audiovisual consumption and fostered the emergence of new narrative forms (Lastra, 2016).

In this context, the traditional "one-to-all" model once practised by mainstream media has evolved into a new dialogical "all-to-all" model characteristic of digital media (Aparici & Silva, 2012), now led by these prosumers. Indeed, some of these new users have successfully adapted to the changing landscape of social media and, in doing so, have become professionalised alongside the platforms themselves. As a result, this category of prosumers has focused its efforts on building an audience to whom they can deliver credible, high-quality content –thus transforming into influencers (Arranz & Ortega, 2021). This new reality has been made possible by social networks featuring persuasive audiovisual formats –such as TikTok, YouTube, and Instagram– because young people perceive them as more approachable, informal, and entertaining than traditional media. Furthermore, they provide intuitive editing and distribution tools that allow users to become content creators with potentially global reach (Pérez-Escoda *et al.*, 2024).

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According to the *White Paper on Influencer Marketing*, influencers are defined as individuals with sufficient potential to stimulate conversation, generate engagement and/or influence the purchasing decisions of a target audience. In this regard, it is essential to distinguish between native and non-native influencers. The first group comprises individuals who first gained recognition through social media and built large followings as a result of the activities and content they share on their profiles. The second group refers to non-native influencers –those who already had established careers or public recognition and who subsequently built a substantial online following by leveraging their pre-existing reputation (IAB Spain, 2022). The present article focuses on the first group: native influencers.

Campbell and Farrell (2020) categorise native influencers according to their number of followers on Instagram (although classifications may vary by country, platform or thematic focus):

1. Nano-influencer: at the early stages of their influencer career, with fewer than 10,000 followers, mainly comprising friends, acquaintances and people in their immediate environment.
2. Micro-influencer: successful enough to pursue influencing as a profession; their audience is typically concentrated around their geographical base, ranging between 10,000 and 100,000 followers.
3. Macro-influencer: enjoys significant success, though not yet fame, with an audience between 100,000 and one million followers.
4. Mega-influencer: has experienced such remarkable growth—reaching or surpassing one million followers—that they have achieved a certain celebrity status.

It is worth noting that the term "influencer" first appeared in connection with YouTube, referring to users who produced videos exclusively for the platform. Instagram later adopted it in relation to image-based content (Arranz & Ortega, 2021).

1.3. New Narratives on Social Media

The present study focuses on the discourse shared by people with rare diseases on social media –specifically on Instagram– intending to analyse the motivations and expectations of individuals with an RD when creating personal profiles in which they share information about their condition and daily life, as well as the consequences that such public exposure may have for their self-esteem and emotional wellbeing.

To date, research in this field has primarily centred on the social network X (formerly Twitter). Some authors have examined the interactions between rare disease patient associations and other users or opinion leaders on the platform, aiming to identify strategies used to raise awareness, educate, and inform about rare diseases and the challenges they present (Pérez-Dasilva *et al.*, 2021). Others, such as Martínez-Martínez *et al.* (2023), have chosen to study the messages and content shared on X during Rare Disease Day to identify the leading actors and topics of discussion.

Meanwhile, Sánchez-Castillo and Mercado-Sáez (2021) conducted an analysis of the social network TikTok, where they observed a more individualised discourse around rare diseases –one in which each patient presents their daily life and

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the needs and difficulties arising from their condition. Similarly, Willis *et al.* (2023) interviewed various American patient-influencers, including some with rare diseases, intending to explore how these users communicate health-related knowledge to their follower communities.

In terms of methodology, these studies combine both quantitative approaches (mainly content analysis, but also online surveys distributed in collaboration with patient organisations) and qualitative ones (through discourse analysis and, more commonly, semi-structured interviews). Although most favour one approach or the other, some –especially the more recent– employ mixed methods (Yabumoto *et al.*, 2022).

However, no study to date has explicitly investigated the motivations and expectations of people with rare diseases when it comes to presenting their own image in digital environments, nor the impact that this online activity may have on their mental health as content creators. This underscores the importance of initiating a line of research that sheds light on the production phase of the content these individuals share on their networks –enhancing our understanding of the underlying characteristics and principles that shape the creation of content focused on rare diseases and the disabilities often associated with them. At the same time, it will help to comprehend better the psychological consequences that online actions and interactions may have for individuals living with health conditions as specific and complex as rare diseases.

The general aim of this study is therefore to understand the motivations, expectations, gratifications, and dissatisfactions experienced by people with rare diseases who participate in social media through personal profiles, where they communicate about their illness and their everyday lives. More specifically, the study sets out to achieve the following objectives:

SO1: Identify the particular reasons that led them to create a personal profile on Instagram.

SO2: Determine whether these reasons were related to their disease.

SO3: Identify whether their primary motivation was to raise awareness or disseminate information about their condition.

SO4: Explore whether their communication about their illness follows a strategic (institutional, personal, or economic) perspective.

SO5: Examine their perceptions of the risks involved in their participation on social media, such as hate speech, overexposure, or vulnerability.

This research, therefore, explores how these young people challenge the traditionally passive roles assigned to individuals with rare diseases and disabilities, positioning themselves instead as active content creators –some of whom achieve notable success. To this end, the study has been guided by the following research questions:

RQ1: What motivates people with rare diseases to share content about their condition on Instagram?

RQ2: How do they perceive the emotional benefits and drawbacks of having a social media profile dedicated to their illness?

2. Methodology

In the first phase, the personal profiles that would make up the sample were selected. To this end, the database from the project "Identification of the Socio-Health Needs of Patients with Rare Diseases: Processing of the Communicative Flow on Social Networks," funded by the Conselleria de Educación, Universidades y Empleo of the Generalitat Valenciana, Spain (CIAICO/2022/188), was used. One of the researchers involved in the present study was also part of this project. This database, which included social media posts relating to 30 of the more than 4,000 pathologies registered in Orphanet, enabled the identification of 2 of the profiles (I6 and I8) selected for this study, as well as the compilation of a list of rare diseases used to locate additional potential interviewees on Instagram. In addition to the reasons outlined in previous sections, this platform was chosen because it has, in recent years, been the social network with the third-highest number of active users, after Facebook and YouTube (We Are Social *et al.*, 2024). Accordingly, an initial group of 32 Instagram profiles belonging to people aged between 18 and 35 with rare diseases was established. Potential participants were then contacted via their Instagram profiles and informed of the research objectives, as well as the procedures for recording, transcribing, and anonymising the interviews. Twelve individuals responded to this message. Although not all ultimately participated, the initial encounters led to the identification of two additional profiles that could be included in the sample, and they were then contacted using the same procedure.

A reminder message was sent to those who did not reply within one week. After this follow-up, three declined participation due to health reasons. In another case, the person refused to participate because they did not consider themselves an influencer, despite having 217,000 followers. This illustrates the complexity of approaching such profiles and the varied connotations associated with the term 'influencer'. Ultimately, ten people agreed to participate in the study, representing approximately one-third of those initially contacted. Participants were again informed about the study's objectives and how their data would be handled. Anonymity was guaranteed to foster an atmosphere of trust during the interviews, allowing participants to feel more comfortable and free to share their experiences openly and honestly. Beyond safeguarding their personal well-being, the value of their testimonies was considered not so much in terms of their individuality, but as representatives of a broader profile: people with rare diseases who contribute to social debate by publicly sharing a collective reality.

The interviews were conducted using a semi-structured questionnaire (Appendix I), designed to address the research questions and objectives. All interviews were carried out online via Microsoft Teams, recorded with participants' consent, and subsequently transcribed. The most extended interview lasted 52 minutes and 29 seconds, and the shortest 19 minutes and 15 seconds, with an average duration of 24 minutes. None of the participants received any financial or other form of compensation for taking part. The transcribed material from the ten interviews conducted constitutes the dataset analysed. Data mining and coding of the interviews were performed using the Atlas.ti 25 software.

Regarding the interviewees' profiles, eight were women and two were men. As mentioned earlier, their ages ranged from 18 to 35 years, with an average age of 28.1 years. In terms of their reach and following the classification proposed by Campbell and

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Farrell (2020), two participants fell into the category of macro-influencers, six into that of micro-influencers, and two were nano-influencers (see Table 1).

In other types of profiles, being an influencer often involves participating in advertising campaigns or brand collaborations. In the case of the profiles analysed, three participants had not received any brand offers since creating their accounts. In contrast, the remaining seven had received and accepted collaborations –mainly from socially driven organisations, such as associations.

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Table 1. Interviewed profiles

ID	Gender	Age	Condition	Followers	Type of influencer	Profile created
1	Female	26	Agenesis	19,900	Microinfluencer	2021
2	Female	27	Apert Syndrome	19,000	Microinfluencer	2021
3	Female	23	Giant Congenital Melanocytic Naevus	85,800	Microinfluencer	2018
4	Female	35	Takayasu's Arteritis	142,000	Macroinfluencer	2014
5	Female	30	Ehlers–Danlos Syndrome	25,700	Microinfluencer	2024
6	Female	32	Acute Intermittent Porphyria	248,000	Macroinfluencer	2019
7	Female	18	Premature Retinopathy	37,400	Microinfluencer	2018
8	Female	35	Multiple Sclerosis	6,352	Nanoinfluencer	2020
9	Male	34	Albinism	2,648	Nanoinfluencer	2023
10	Male	21	Congenital Laminopathy	25,000	Microinfluencer	2019

Source: authors' own elaboration

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3. Results

3.1. Participating in the Rare Disease Debate First-Hand

Among the interviewees, most decided at some point to reorient their personal Instagram profiles toward content related to disability and rare diseases (n=6). Some chose to create a new account specifically to discuss their condition (n=2), while others integrated information about their illness into their regular posts without altering the overall focus of their profile (n=2) –for instance, maintaining themes such as their profession or lifestyle.

The motivations that led participants to speak about their illness on Instagram were diverse. However, two key aspects stand out: the desire to raise awareness and normalise rare diseases through their own personal stories and the intention to help others who may be going through similar experiences. Indeed, as shown in the word cloud (Figure 1) generated from the interview testimonies, alongside auxiliary and stative verbs, other prominent action verbs include "help," "share," and "talk."

Figure 1. General Word Cloud Generated from Interview Data

The figure highlights a series of action verbs (do, have, say, know, be, talk, help, start, want, find, follow, try, share), as well as several nouns referring to the patient communities being built (disease, network, life, disability, person, collaboration)

Source: authors' own elaboration

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Making rare diseases visible through personal experiences has been one of the primary motivations for the interviewees to share information about their conditions on social media platforms, such as Instagram. Many of these pathologies are unfamiliar to most of society, and the participants emphasised that speaking about their daily lives helps to normalise and integrate people affected by rare diseases and their families.

> "My profile was created to show my day-to-day life, how I get by and how I live with my condition" (I1).

> "I've never seen myself as an influencer or a communicator of rare diseases. I was already communicating, and when this happened to me suddenly, I thought: 'Why should I hide it when I have this platform?' [...] There's a lack of understanding and empathy towards people with rare diseases that often aren't even visible. I have a disability that affects me daily in one way or another. So how could I not talk about it or explain if I'm having a bad day, so that people can understand a little better what it's like?" (I4).

> "My main goal was to make my disease more visible and, if I could help others, then I'd be over the moon. In fact, there are lots of people with other diseases, even their family members, who've written to me privately to say: 'Thank you so much, your videos help me a lot'" (I10).

Narrating their everyday lives has often helped them overcome their own struggles with self-acceptance and reduced the need to explain their condition to new people or groups repeatedly. For instance, one interviewee explains in a video how he replies to WhatsApp (with help from his mother) or Instagram messages (using a computer controller and keyboard, which makes his responses very slow). They also share content aimed at educating others about how to assist them:

> "For example, I made a video on how to help a visually impaired person in the street. And many people told me: 'I saw your video and then helped someone I met." (I7).

Another participant described the sense of "liberation" that came from talking openly about her illness online:

> "At 12 or 13, you start a stage where you become aware of your body. You want others to like you. You notice how people look at you. And of course, I stopped seeing myself through my own eyes and started seeing myself through theirs. [...] A few years later, on social media, there was a hashtag called #paraliberarnos ('to free ourselves'), where people posted pictures of their cellulite or things they were self-conscious about. And I thought, I'm going to take a photo of my scars; I figured: 'People follow me for English and basketball... so now they'll know, and I won't have to explain it anymore.' [...] I did it for my mental health" (I3).

As key actors, they also believe their voices should be present in the public debate on rare diseases. Likewise, social media allows them to reach audiences different from those they meet in talks or conferences.

> "It's something I say often –that we need to occupy spaces and be present" (I1).

> "We have to fight for things to become more accessible, and I realised that social media is a huge gateway to showcase that fight as well. It's a great tool for visibility" (I7).

Another primary motivation for being on Instagram is to provide accessible information, drawn from personal experience and free from medical jargon or technical language, to help newly diagnosed individuals or those searching for content about these conditions. In some cases, they even become role models for overcoming specific barriers.

> "I'm aware that I can help a lot of people" (I1).

> "…I decided I needed to make myself easily reachable. So I thought: 'I'll create an Instagram account.' And I did. [...] I used to share relevant information about the disease –symptoms, treatments, and so on– but on my personal Instagram, I began with my story, my before and after, my paralysis, explaining what it was, and I saw that my way of doing it worked better. So I decided to merge the two" (I6).

> "After a few difficult years personally, I decided to research more about albinism. I realised there's very little, if any, content on social media about it. [...] So I thought: 'Why not start a project online? I think it could help both the albino community and others to understand us a little better when they see us'" (I9).

> "Do you have multiple sclerosis? Okay, so she does too –and she can do this and that and play sports" (I8).

In the context of this normalisation process, most participants also take part in visibility campaigns on 28 February, International Rare Disease Day, as well as on the day dedicated to their specific condition. Although they believe visibility should be ongoing, they acknowledge that such commemorations help society to keep them in mind.

> "I hope the day comes when it's no longer necessary to remind people, but I think we're still at a stage where social presence is important –being seen, being heard and bringing these realities closer to others" (I1).

> "When it's World Rare Disease Day, 28 February, I always post something as a reminder or a video. I think it's important to celebrate it so we realise how little is actually being researched or invested in –ot only in my disease, but in any of them" (I10).

3.2. The Two Sides of the Coin

For individuals with rare diseases, the emotional benefits of being active on social media often outweigh the potential drawbacks. For all the interviewees, their Instagram profiles –despite the public exposure they entail–have proven to be a positive experience overall.

3.2.1. Empowerment and Network Building

The main benefit they identify in having a profile dedicated to their rare disease is a sense of usefulness –a feeling that their content not only helps others but also enables them to understand themselves better, gain empowerment, and reflect on their own condition.

> "It helps me enormously, because I'm still a person who has insecurities. It strengthens me and gives me motivation" (I1).

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> "To raise awareness and, above all, to share with doctors and medical students what I was also learning" (I2).
>
> "Social media helps people, but the first person it helped was me" (I3).
>
> "There are so many people –more than I could ever have imagined– who've thanked me for posting my videos. I never expected to receive such feedback. It's deeply fulfilling" (I5).
>
> "I've connected with people with whom I've shared very personal, sometimes quite profound experiences. It's really helped me to get to know myself better" (I9).

Another key point raised by participants is the extensive network of contacts they have built with others who share their condition. In some cases, they have even helped to create or join broader communities that exceed the number of cases any medical specialist might encounter in their career.

> "Since starting on social media, I've been in touch with lots of families. I've even set up a group with some of them, and we've met up a few times" (I1).
>
> "I've found people who share my specific disability –people who discovered me through social media and who might never have known anyone else like them. For them too, it's a support network that's being built" (I2).
>
> "I've met so many people thanks to Instagram. People write to me from all over the world – Latin America, New York, India... In the end, thanks to that, I know more people with my disease than my doctor does" (I4).
>
> "There are children who've been diagnosed because their parents saw one of my videos. And some people don't feel alone –even if they don't have the same illness as me– because we've formed a little community, we talk to each other" (I5).
>
> "I've connected with so many amazing people. I've made new friends thanks to it, and above all, we understand and support each other. I've built a large community of patients who follow me and feel the same way" (I6).

Their presence on social media also gives them greater visibility in both traditional and online media, along with a certain degree of popularity and social recognition.

3.2.2. Dealing with Hate and Loss of Privacy

Daily exposure on a popular social network like Instagram inevitably entails certain emotional drawbacks. The main challenge identified by participants is dealing with negative comments from some users, often shielded by the anonymity of fake accounts. Although most interactions they receive are positive, at times they must manage hate and personal insults.

> "Once someone wrote something like 'go die', something horrible –and in that case, I did expose them in my Stories, mainly to highlight how much hate there is and to show that we shouldn't stoop to that level" (I6).

The most common negative comments tend to target physical appearance (when the rare disease is visible) or attempt to downplay the seriousness of their condition (when symptoms are not outwardly apparent). In such cases, most choose not to respond –unless the attacks are particularly degrading towards the community they represent. However, when a video goes viral and reaches a broader audience, the likelihood of receiving negative comments increases.

> "I reply when I think I can add something, or when there are people –especially on Instagram– who aren't being hateful so much as ignorant. The comments can be a bit harsh, but if it's out of ignorance, I respond. If it's just to provoke, I let it slide" (I2).

> "The more viral the video gets, the higher the percentage of hate. In fact, I had a super-viral video, with over six million views, and I had to disable comments because it was just a barrage of hate" (I5).

> "In reality, I've always had more positive than negative experiences. But I'm aware that the greater the exposure, the higher the chances of it happening" (I7).

> "I always reply. I even ask some people why they think that way" (I8).

All participants note that negative interactions remain a minority, since most of the messages they receive are supportive and encouraging. Overall, they view their presence on social media as having more advantages than drawbacks. The gains in social visibility and self-esteem clearly outweigh any isolated negative experiences they may face.

Another concern mentioned by several interviewees is the risk of losing their individual identity and being seen solely through the lens of their illness. They stress that their posts are precisely aimed at showing their everyday lives –to make visible the person behind the condition.

> "I don't want to be that girl who only talks about this disease" (I4).

Finally, another issue raised in the interviews is the concern about the loss of privacy. However, as they are not professional influencers, participants feel they have more freedom to decide what and when to post.

> "It's really hard for me to find the limit between what to post and what not to post, because I like to keep my private life to myself. It makes me uncomfortable for people to know what I'm doing or how my life is going. I like to share only what I feel like sharing" (I3).

3.3. Rare Diseases Don't Sell (Yet)

Although participants acknowledge that social media provides them with a certain degree of public exposure –leading to invitations to talks and events– the situation changes when it comes to the potential monetisation of their profiles. With the exception of one participant whose account focuses on lifestyle content and reports earning approximately 80% of her income through Instagram, most have received few, if any, offers from brands, aside from occasional collaborations with socially driven companies or non-profit organisations. In most cases, they express openness to potential partnerships, provided the brands

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align with the values of normalisation and inclusion that they promote through their profiles. However, they also recognise that such collaborations are neither easy to secure nor necessarily desirable for everyone.

> "I think the healthiest way is to have a stable salary on one side and treat social media as a hobby" (I3).
>
> "I get a lot of offers from supplement companies, but I always say no because I'm not going to tell people what they should or shouldn't take" (I5).
>
> "Many brands aren't used to collaborating with people with disabilities because there simply aren't that many profiles" (I7).
>
> "What I do is share my life, help others –I don't want to make money from this, I don't think it's necessary" (I8).
>
> "I'd love to, because I've always been interested in social media, and it would be amazing if a brand wanted to collaborate with me. I'd love that" (I10).

4. Discussion and Conclusions

Regarding the first research question –What motivates people with rare diseases to share content about their condition on Instagram?– the analysis of the interviews reveals that the primary motivation is to participate in the social debate about rare diseases firsthand. Indeed, most participants eventually chose to reorient their personal Instagram profiles towards content related to their disability or illness. This participation manifests in two key ways: sharing personal experiences to raise awareness and normalise rare diseases and helping others facing similar situations.

The findings reveal that people with rare diseases use Instagram to demand visibility for their condition throughout the entire year –not just on awareness days. While they appreciate and promote initiatives that flood social media with content about rare diseases on specific dates, they call for sustained visibility that leads to long-term awareness and inclusion. This demand echoes similar calls from other vulnerable or stigmatised groups, such as the LGBTQ+ community, which advocates for the ongoing expression and recognition of their rights –making their realities visible continuously rather than only on symbolic dates (Barroso-Moreno *et al.*, 2023). Social media, therefore, emerges as an open space for participation, enabling the dissemination of advocacy discourses that legitimise the expression of personal identities.

A further motivation for using Instagram is to provide accessible information drawn from personal experience. Participants believe that sharing their daily lives helps to normalise and integrate people affected by rare diseases and their families. Again, this motivation parallels other social movements, such as body-positive activism, where individuals publicly express their vulnerabilities on the belief that sharing personal experiences not only denounces fatphobia in all its forms but also raises public awareness and visibility around it. Moreover, this activism is intersectional, embracing other marginalised embodiments, such as disabilities (Martínez-Sariego, 2022).

Regarding the second research question –What benefits and drawbacks do people with rare diseases perceive from maintaining a social media profile about their condition?– the interviews show that all participants find their Instagram experience to

be positive, despite the high degree of public exposure it entails. The main emotional benefit they identify is the sense of usefulness and gratitude: not only do their posts help others, but creating content allows them to know themselves better, feel empowered, and reflect on their condition. Another key benefit is the extensive network of contacts they have built with people who share the same disease, thus creating or joining communities of information exchange and shared experience.

Nonetheless, daily exposure on a prominent platform like Instagram also brings certain psychological drawbacks, the most significant being the need to manage negative comments. Most participants choose not to respond, unless the comments are particularly harmful to the community they represent. Another concern mentioned by several interviewees is the risk of losing their individual identity and being seen solely through the lens of their illness.

4.1. Study Limitations

Despite the contributions mentioned, this study presents several limitations that should be considered in future research. Firstly, a larger and more gender-balanced sample would be desirable. Although this study includes more women than men –a notable contribution to the field– it would be valuable to include more male influencers to achieve greater representativeness. This would enable the comparison of male and female narratives, identifying both shared and divergent elements. It is also worth noting that this predominance of women could reflect greater female participation in this type of discourse –a hypothesis that future studies could help confirm.

In terms of representativeness, future research could include a broader range of participants encompassing nano, micro, macro, and mega-influencers, as well as a wider age range. Moreover, the age range of interviewees could also be broadened to include profiles from a wider variety of age groups. This expanded scope could yield valuable insights into how people with rare diseases across different generations utilise social media, as well as the respective benefits and drawbacks it entails for each age segment.

It is also worth noting that the present study assigns equal weight to each condition. However, future research could profitably examine specific rare diseases in relation to more quantitative aspects, such as the reach of their influence, the amount of hate they receive, or the degree of empowerment achieved through positive feedback. Such an approach would make it possible to understand and analyse the impact of visibility and social media exposure –particularly on Instagram– on participants' lives and emotional wellbeing, distinguishing between subgroups according to each rare disease.

Accordingly, future research could expand the number of interviewees in line with the limitations identified here (sample size, gender, influencer classification, age, and disease type) in order to determine whether the same motivations are shared and to establish patterns within each group, thereby gaining a deeper understanding of this community and its relationship with digital platforms.

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Data collection and analysis	Gisela Ramírez-de-Arellano-Fambuena, Lucía Sapiña and Josep Solves
Discussion and conclusions	Gisela Ramírez-de-Arellano-Fambuena and Lucía Sapiña
Drafting, formatting, review and approval of versions	Gisela Ramírez-de-Arellano-Fambuena, Lucía Sapiña and Josep Solves

7. Conflict of interest

The authors declare that they have no conflicts of interest.

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9. Apendix

Appendix I. Interview Questionnaire

Sociodemographic Data

- Gender
- Age
- Rare disease (RD)

Personal profile

- What does your condition involve? Briefly describe your story.

Intent and Presence on Social Media

- When and how did you decide to start using social media?
- What was your intention when you opened your Instagram account? Where did the idea come from? Was it the result of personal reflection? Did you discuss it with anyone in your family or social circle?
- Were you used to speaking publicly about your condition?
- Did you create a new account specifically to raise awareness about your condition, or did you use an existing account and gradually begin to post more about your RD?
- When did you realise that this type of content might interest people?
- Do you consider yourself an activist for rare diseases?

Visibility

- Why do you think it is important to raise awareness about rare diseases and disability? Do you think there is still little visibility and/or that stereotypes persist?
- What do you do personally to increase that visibility? Do you focus more on your rare disease, your disability, or both equally?
- Do you consider international awareness days for the different RDs important? Do you think they have enough impact to raise awareness?
- Since creating your social media profile, how have you felt emotionally? What impact do you think your online presence has had on your well-being?
- Have any brands approached you for collaborations?

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- Have you been invited to give talks, attend conferences, or participate in programmes as a result of your profile?
- Have you been asked to write any articles?
- Have you received any awards or recognition for your content?

Feedback on Social Media

- Do you receive hate (negative comments)? What kind, and what do they focus on?
- How do you feel about this hate? How do you interpret it?
- Do you think it is necessary to respond to negative comments? Do you think it is important to do so to make your discomfort visible?

Focus and Future of the Profile

- Do you monetise your social media activity?
- What plans do you have for your content?
- Summarise in one sentence the message you want to convey as an influencer/activist.

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