

## Use of Web 2.0 in virtual communities of patients with rare diseases in Spain

*Uso de la Web 2.0 en comunidades virtuales de pacientes con enfermedades raras en España*

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This work aims to ascertain whether the communication resources of the Web 2.0 used in virtual communities of patients with rare diseases successfully provide useful information and improve the health conditions of those affected by rare diseases. This observational study conducted on the websites of 80 organizations shows that these communities of social networks are indeed the preferred means of health-related communication for those affected and they provide a helpful mutual support network. The collective knowledge generated fosters co-participation in decision-making and provides a more focused approach to care for patient needs.

**KEYWORDS:** Diseases, patients' portals, social networks, communication in health, Web 2.0.

*Este trabajo trata de conocer los recursos de comunicación de la Web 2.0 utilizados en las comunidades virtuales de pacientes con enfermedades raras y comprobar si responden a sus necesidades informativas y mejoran su condición sanitaria. El estudio observacional de las páginas web de 80 organizaciones muestra que estas comunidades y sus redes sociales digitales son los medios preferidos para la comunicación en salud y para proporcionar apoyo mutuo. El conocimiento colectivo generado favorece la coparticipación en la toma de decisiones y proporciona un enfoque del cuidado más centrado en sus necesidades.*

**PALABRAS CLAVE:** Enfermedades, portales de pacientes, redes sociales, comunicación en salud, Web 2.0.

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## INTRODUCTION

The habitual use of the Internet by the Spanish population to search for information on aspects related to health and disease has caused the digital divide to be, at present, almost non-existent in the Spanish population. A progressive increase in both the quantity and in the intensity of the use of the Internet has been observed (Organisation for Economic Co-operation and Development [OECD], 2001).

This growth maintains its trend, showing results of 84.60% usage in 2017. The study shows that people who use the Internet to search for health-related information account for 49%, highlighting the increase in people who use the Internet to upload content created by themselves and to be shared, reaching up to 31% (Observatorio Nacional de las Telecomunicaciones y de la Sociedad de la Información [ONTSI], 2017a).

A subsequent report indicates that 35.5% of network users utilize blogs and forums to obtain information, 62.6% consider the network an informative space on topics of interest and another 35.4% as a means of sharing relevant aspects such as news, images or videos. The report also shows the continued increase in users, reaching 86.4% and highlights the search for information as the majority use (84.4%), followed by e-mail (78.5%) and instant messaging (76%) (ONTSI, 2019).

Data show that daily use of these technologies has been a great social innovation, especially relevant in the search for topics on health and disease, thus offering benefits by providing extensive information –both in quantity and in a variety of access forms–. However, highlighting this virtual information can also present challenges related to its quality if the access sources do not present sufficient scientific guarantees and aren't duly accredited and updated (Muñiz et al., 2007).

In order to have quality guarantees, it is recommended to use the websites of official organizations and those of patient organizations that inform and train on health habits, favor shared decision-making and improve interaction between their users thanks to Web 2.0 tools such as blogs, discussion forums and social networks, mainly (Lorente Armendáriz, 2002). Web 2.0 is a new “social software” that changes the traditional flow of information by allowing Internet users to

be, simultaneously, receivers and senders of information. In this way, the network becomes a source of social dynamics, a space for participation and social interaction of a cooperative and collaborative type (Armayones, Requena et al., 2015). Participants in these digital platforms use the transforming power of communication to organize themselves (Treré, 2016) and promote social changes that favor their needs and interests (Treré, 2014).

For this reason, the associations' portals must meet the quality and reliability criteria for health-related websites established by the Commission of the European Communities (2002) –referred to the current European Union since 2009–. The most prominent criteria are integrity of purpose and objectives that present updated and verified information by experts and accessible content that favors reading or listening in cases of disability (Farjas & Serrano, 2007).

Other authors also recommend that the structure of these pages should be clear, with a menu to facilitate navigation and that it should include an updated news section (Lorente Armendáriz, 2002). Virtual patient communities (VPC) should be able to select and manage the most relevant information, eliminate incorrect information and become knowledge portals (Sánchez Arce & Saorín, 2001).

Thus, the importance of use of Information and Communication Technologies (ICT) in the field of health is observed, with the new paradigm of what is known as 4 P's medicine: personalized, predictive, preventive and participatory. The 4 P's paradigm is closely related to the current information exchange systems among the users themselves. The last "P" is especially significant because it encourages "a system whose center is the patient". This situation entails a fundamental change in the relationships between patients and the health system, which materializes in a more active, participatory and co-responsible type of user in decision-making based on the information found on the network (ONTSI, 2017b).

The network's accessibility in obtaining health information has induced a cultural change and facilitated the development of VPC, thus turning people affected by disease into managers of their health condition. Cyberculture reconfigures the previous patterns of social relationship by acting as a mediating tool which, starting from

the interaction and collaboration between its users, turns these virtual spaces into communities of dynamic knowledge and learning—different and greater than those instead provided by the traditional health profession—(de Melo & Vasconcellos-Silva, 2018; Pineda et al., 2013).

The transformation of personal experience into knowledge favors the development of the associative movement, as reflected in Law 41/2002, of November 14<sup>th</sup>, basic regulation of patient autonomy and rights and obligations in the field of information and clinical documentation (Farjas & Serrano, 2007). This associationism, based on the need of patients with Rare Diseases (RD) to know more about their social and health problems, favors their immersion in a community to share scarce information and increase it. Thus, the classic profile of an inactive patient is modified, causing a new profile to emerge that now makes the patient one of the most active social agents in the management of health information and who manages specific aspects of the disease more autonomously (Requena, 2014).

The experiences of people affected by RD—both patients and relatives—are transformed into knowledge (Castillo et al., 2015), and have the effect of decreasing their feeling of isolation and discrimination and help them respond to their emotional needs (Torrente et al., 2010). This newfound collective intelligence allows applying the experience of people affected by RD to better address medical care and meet the patients' needs.

To study and analyze these virtual organizations, as well as the interaction between their users, a method of social observation could reveal some key aspects, the method is called *netnography* (Kozinets, 2002), which is ethnography applied to research on the meaning of communities on the Internet and their typology (Hine, 2004; Washington Turpo, 2008). Observing from an ethnographic point of view gives an idea of how the Internet becomes—simultaneously—a medium that represents and gives meaning to the current world and an actor that constructs reality itself, based on the uses that are made of it.

In this way, social networks are conceived as accounts and social spaces in which the experience of their users is essential for their functioning as informative and emotional support (Castillo et al., 2015). Both face-to-face and virtual communities are considered social

networks because they have the same objective: to connect people who maintain relationships with each other that will affect the subsequent behavior of their members (Wellman, 1997). The differences lie in the fact that the communication established in the virtual communities is carried out remotely through the Internet –instead, face-to-face exchanges take place in person–. Therefore, Internet communication, by being more dispersed and distant, presents the advantage of being able to avoid certain unwanted options.

In this paper, equivalent concepts such as virtual patient communities, online patient portals, as well as online patient organizations and associations will be used. All of them are virtual communities that bring together people whose common interest is to be affected by RD and who interact and collaborate through different Internet resources, mainly Web 2.0.

The potential of Web 2.0 to generate content and manifest its needs encourages the emergence of *e-patients*, defined as people affected by a disease who use Information and Communication Technologies (ICT) appropriately to obtain information and become empowered patients capable of managing some conditions of their pathology (Ferguson & Frydman, 2004).

There is a parallel development of these forms of “cyber community” along with the new role of an active patient who considers health as an individual good and as a right. This type of patient, expert and reflective, takes into account other people’s experiences and develops an important potential to apply them in shared decision-making. This new type of patient participates in organizations that represent the interests, needs of those affected and chooses to access quality information in regards to health (Fernández, 2004; Muñoz et al., 2007).

In the case of the group of people affected by RD, this phenomenon manifests itself remarkably, with RD affected people being one of the most proactive groups of users on the Internet (Armayones, Requena et al., 2015). People affected by RD share health information and develop virtual communities and specialized social networks such as RedPacientes.com, Rare Commons, RareShare and RareConnect or more generic networks such as Facebook or Twitter, in order to attain greater social presence, manage and disseminate information, maintain

contact with their users, make their voices heard by public health organizations to claim their interests and encourage the development of research and healthcare improvement (Aldamiz-Echevarría et al., 2008; López Villafranca, 2014).

### VIRTUAL COMMUNITIES OF RARE DISEASE PATIENTS

In the “Network Society” (Castells, 2006), the Internet has contributed to the development of numerous social networks in different areas of social life and, of course, also in the health field. This article deals specifically with how the virtual communities of patients with rare diseases in Spain, along with their associations and organizations, increasingly use the various tools available on the Internet to share information about their health problems and make their needs and interests visible (Baeza-Yates & Saint-Jean, 2003). The virtual space reduces isolation and acts as a resonance to achieve socio-health care more tailored to the needs of those affected.

The predominant profile of the most active user corresponds to the female sex. Most of the participants are married women with a high educational level. The importance of women, in the provision of informal care, as health agents of the family nucleus is evident (Dominguez-Serrano et al., 2011; Gené et al., 2008). In the case of relatives of patients, it is also observed that the majority of active users are wives, mothers and daughters (Fernandes et al., 2018; Sallfors & Hallberg, 2003).

The average age of the participants is 43 years old –which is in line with the reproductive age of the parents, since most of the people affected by these pathologies are children–. Out of those participants, 93% of fathers are employed compared to 66% of mothers, 31% of parents quit their jobs because of their child’s illness (Tozzi et al., 2013).

The study of the features most accessed by users of association portals is indicative of their predominant interests and needs (Baeza-Yates & Saint-Jean, 2003). The analysis of the use and activities of the VPC shows that the most frequently accessed features are the exchange of information on the clinical manifestations of the disease, its evolution and the results of the treatment (Fernandes et al., 2018).

The information obtained impacts decision-making in various ways: the change of medical professionals (11%), the modification of the children's eating habits (24%), as well as discussing the information obtained online with the doctors who already followed the case (70%) (Tozzi et al., 2013). The results indicate that the information obtained had the result of an increased understanding of the disease but also caused an increase in initial anxiety in parents (Castro & García-Ruiz, 2014; Tozzi et al., 2013).

Regarding the relationship between the patients and the health system, a paradoxical fact is revealed. Although these patients are proactive in managing their pathology, there is no reciprocity on the part of the health organization –such as socio-health care centers and their professionals– to stimulate and favor the patient's participation in the process (Fernandes et al., 2018). Other authors also highlight the difficulties of health professionals in assuming this model of active participation, since they do not understand the potential of network interaction behavior with patients and/or caregivers (Tozzi et al., 2013).

Some studies identify the influence of the newfound virtual connectivity dimension with the adherence to treatments by VPC users. VPC is an effective tool that favors a better acceptance of the disease, reinforcing a sense of group belonging also thanks to mutual support. Virtual interaction between patients and those affected allows the incorporation of a more subjective type of information –emotions, feelings–, different and complementary to that of the scientific type and it enables patients to feel encouraged and empowered. The lack of dialogue and guidance in traditional medicine would explain why patients try to resolve doubts and seek guidance by creating and participating in virtual health networks. The recommendations of expert patients and sharing personal experiences have shown to improve adherence to treatment (Fernandes et al., 2018; García, 2014; Requena, 2014).

The improvement of self-esteem, based on the interaction and creation of social bonds in the virtual community, can be combined with other forms of face-to-face social relationships, as can be seen in the activities carried out by the stakeholders such as orientation workshops and information days (Herrero et al., 2004). Users of these communities positively evaluate the influence that their participation

has had in the perception of their disease (35.6%: very positively; 45.2%: quite positive; 17.8%: without incidence, and 1.37%: quite negatively) (Grau, 2014).

Some studies describe the functions of the most important RD specific social networks such as RareConnect, created by the European Organization for Rare Diseases (EURORDIS) and the National Organization for Rare Diseases in the United States (NORD), and Redpacientes, made up of professionals and patients. Their importance is based on their role as decision-making facilitators, consistent with access to more information and training (Arroyo, 2014). The author considers that there are also other ways to increase the visibility and offer information, current news and events of RD associations through general social networks such as Facebook and Twitter.

## METHODOLOGY

This paper analyzes how the communities of patients with rare diseases establish actions on the Internet, through their portals or 2.0 Web pages and what type of interactive tools are available on their interface.

After preparing a list of virtual RD associations, this paper will identify the operation and characteristics of the users of their web pages and whether access to the different resources is easy and intuitive or, conversely, presents some type of interaction difficulty for its users.

### *Specific objectives*

1. Determine the most used communication instruments –blogs, forums and social networks, among others– and analyze the way they are used to generate the content they show.
2. Demonstrate how the different existing spaces favor the exchange of information and the interaction between its participants.
3. Analyze the use of different virtual social networks –specific or generic–, which are most widely used by these associations.

The main hypothesis pivots on the assertion that the use of ICT tools by organizations of people affected by RD is increasing along with the network-society at the end of the 20<sup>th</sup> century. Network-society is based on information and communication system technology through

the Internet (Castells, 2006) which is being increasingly implanted in all spheres of everyday life for the Spanish population and, particularly, in the area of health. The instruments available in the VPC facilitate informative, formative and mutually supportive functions and they offer the possibility to researchers, scientists and health professionals to use the information and apply it in the treatment of these diseases.

### *Methodology*

Cross-sectional observational research design has been carried out in order to estimate the presence and use of more frequent interactive 2.0 tools used by virtual communities of patients with rare diseases. Specifically, this research aims to analyze the profile of virtual social network accounts and, within those, the interaction between patients who access those social network accounts. The present investigation was carried out during the period between September 1<sup>st</sup>, 2018 and January 23<sup>rd</sup>, 2019, applying the following analysis strategy:

- Phase 1. Search for rare diseases in representative institutions of these pathologies:

*Orphanet*. The website offers a list of 1 179 pathologies in alphabetical order. The high number of existing pathologies –classified from groups of disorders, and clinical, etiological or histopathological subtypes– added to the fact that some diseases are included in organizations that are not specifically dedicated to RD and posed problems in extracting the associations, which in turn limited the search in specific RD portals such as FEDER and EURORDIS.

*FEDER*. A link with direct access to the associations representing the different RD, 346 national entities and a list of 2 572 pathologies at the time of the study appears on its website.

*EURORDIS*. The link “our members” allows the download of the list and map of its associates, arranged alphabetically by country. It represents 826 organizations of RD patients in 70 countries and covers more than 4 000 pathologies. In Spain, it includes 76 associations.

- Phase 2. Preparation of an Excel table of values. The table of values lists the associations representing the different pathologies found in the two referred organisms and data crossing was performed to

avoid duplication and not to miss any association, resulting in a total number of 346 associations.

- Phase 3. Selection of the analysis sample. From all the associations found, a representative sample was chosen using the following criteria:

*Exclusion criteria.* The following associations were excluded:

1. Those that did not have a Web 2.0 page, since a key aspect of the analysis was the process of interaction between its users: 43.
2. Those who ceased their activity during the period of research: 8.
3. If they had no presence on social networks: 27; or they had a presence on social networks, but their website did not link directly to them: 3. Both types were excluded since, although their website was type 2.0, they did not meet the objective of facilitating the interaction of their users from the VPC and their social networks –the central objective of the analysis of this study–.

*Inclusion criteria.* Of the resulting associations, those that met one or both of the following criteria were included:

1. To be a national reference, considering that it could include more participants than in the case of provincial or local associations: 74.
2. Includes in its name the concept of RD: 6.

The resulting final sample is made up of a total of 80 associations.

- Phase 4. Preparation of data collected in an Excel table for analysis. This table contains the contents and activities of the web pages of the associations included in the sample.
- Phase 5. Analysis and discussion of the results obtained. The data obtained allow a general approach to the typology of tools present in the associations' VPC, the most widely used, who uses them and how they are used, as well as what are the contents and the possibilities of interaction present.

To carry out the analysis, the work of Muñoz et al. (2007) is taken into consideration, which implements the organization of knowledge on the website [Pacientes.org](http://Pacientes.org). On this website, the tools used are structured into two basic pillars –content and services– with a documentary architecture that enhances social interaction (Muñoz et al., 2007). The contents show documents and articles, reviewed and analyzed

by experts, information on health policies and plans, explanations of clinical terminology and diagnostic explorations and a section of the current regulations on patient rights. As for services, both the website and the e-mail allow interaction and sharing of experiences and relationships with the health system and its professionals, promoting the dissemination of the associative movement and its activities.

## RESULTS

1. Of the 346 associations that appeared in the list during the analyzed period, only 43 of them (12.5%) did not have a portal or web page based on Web 2.0 technology. In the latter, access to the portal and its viewing is free for anyone interested.
2. The association portals present a similar structure of the web page with direct links to:

*Contact information.* Postal address, e-mail and telephone. These data are present in all associations (100%).

*Forums.* In 75% of cases it is a closed forum that requires prior registration as it is one of the preferred tools for exchanging information on private matters.

*Blog.* This provides information on personal content and experiences of patients themselves or their families. Most are open access (91%).

*Audiovisual resources.* One of the most used resources by associations. It should be noted that 27.5% present at least two resources of this type, the most frequent being YouTube (55%) and Instagram (19%). The use of videos in which personalities from the cultural and sports world offer their support through solidarity activities—mainly sports—to raise funds is highlighted.

A relevant fact is that only two associations present better accessibility options on their web pages, where they allow to choose a larger font size and contrast, both features being related to vision impairment.

Presence in social networks:

*Generic.* Facebook is the most used. It is present in all associations and only one of them works as an exclusive group for members. The communities in this network stand out for being mostly open, 68 com-

pared to 12 that are closed. Twitter is present in 81.2% of them. Note that 80% of associations have a profile on both networks.

*Specific to RD.* In the analyzed pages, access to these networks has not been found, although it is confirmed that they do have a presence on them. Structured into specific virtual communities and discussion groups on specific aspects of the disease for patient groups around the world, RareConnect has a profile on Facebook and Twitter. Guia-metabólica, an organization belonging to Hospital Sant Joan de Déu (Barcelona) offers a specific space, Rare Commons, dedicated to these diseases. Rare Commons recognizes the Internet as a channel of communication, training and empowerment for families, which it calls *e-caregivers*, due to its status as experts in the care of their children. It is present on social networks Facebook and Twitter. RareShare includes health professionals as well as patients and families. It has a specific space for RD and profile associations on Facebook and Twitter.

*Instant messaging.* These newer interaction models like WhatsApp (with several groups, without specifying the number of members) and Telegram (with 73 members), are only specified in two associations, one in each of them.

3. The contents of the web pages collect the most relevant information and news offered in the media, as well as updated scientific articles and other documents from events and conferences dedicated to these pathologies. Most of the information is directed to its users and, to a lesser degree, to other interested persons such as the general population, researchers, health professionals and other recipients. The most important data regarding content are the following:

The most representative, by many, have to do with information on diagnosis, treatment and psycho-emotional support.

Dissemination of research results: conferences, workshops, projects and courses, highlighting that 7 associations produce their magazines.

Raising awareness of what RD are and what they mean for the affected people.

18 organizations highlight the fact of having been declared as Public Utility Entities<sup>3</sup> and other 3 associations present various seals of quality and certification.

4. Concerning health communication aspects, the associations offer informational and emotional support through the interaction between their participants, exchanging personal knowledge and experiences on medical, social and psychological aspects.

Social networks are the preferred channel –with greater activity and interaction among its users– to disseminate information about current events and news. The same does not happen with the more specialized information, of a training and research type, that is offered on the website of each association. Many of these entities recruit personalities from culture and sports industries as spokespersons who promote their project to make it more visible.

5. Organizational characteristics of the communities. Although data on the Board of Directors that form these associations appear on all the websites analyzed, the same does not occur with respect to the data referring to the date of creation of the association –which 66 entities do specify– nor with respect to the number of associated persons –referred only in 9 of them–.

## DISCUSSION

The results of the study coincide with those of other authors (Armayones, Boixados et al., 2015), regarding the use, by association with RD, of the tools of Web 2.0 –highlighting social networks– as promoting interaction and communication between its members. The preferred topics are information and awareness of the pathology and mutual support, both on the website and social networks.

Knowing how and why patients use virtual communities allows the care system to better adjust to their specific needs (Castillo et al., 2015; Tozzi et al., 2013) and overcome the paradox that proactive patients pose in managing their disease without receiving an adequate return from a

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<sup>3</sup> Declaration of Public Utility, in Spain, supposes social recognition of the work of the entity and the possibility of availing of a series of tax benefits.

health system that does not promote their participation in the process. Virtual interaction offers the opportunity to train people affected by the disease (Fernandes et al., 2018; Tozzi et al., 2013).

The communication established in the patient communities, based on collective intelligence, becomes a source of knowledge and produces the empowerment of its users. Knowing the benefits of ICT supposes an advantage that favors the patient-professional interaction and allows adapting care to the needs reported by patients as well as improves the perception of health management in all its biopsychosocial components (Castillo et al., 2015; Herrero et al., 2004; García, 2014; Tozzi et al., 2013).

Despite these benefits, healthcare professionals show reluctance based on the fact that the information obtained can cause harmful behaviors as well as increased anxiety. Because of the current changes, it is imperative that professionals must start an accompaniment process to make recommendations on reliable web pages, resolve doubts and even actively participate in these communities to improve information and training aspects (de Melo & Vasconcelos-Silva, 2018; Tozzi et al., 2013).

## CONCLUSIONS

This work shows how the Internet has enabled the development and growth of social networks in the field of health. People affected by minority diseases have a presence on the network through the portals and web pages of their associations, as well as on the different existing social networks. The results support the idea that active participation in VPC is shown as the preferred means for these society-network to promote knowledge of RD and exchange information and experiences among their participants. In fact, these virtual communities provide mutual support amongst their participants in filling in the void for those patients who need access to care beyond what traditional medical assistance doesn't provide, which in turn also raises awareness within society around these unmet needs.

A similar structure in terms of content and resources is observed on the websites of the analyzed associations. Most present sections of information and current news; both forums in which patients share

personal information—for this reason, most are closed—; and blogs based on the account of personal experiences that allow other people to feel identified by a similar situation, which are mostly open to public view. Audiovisual resources with photographic gallery and videos, generally through links on the YouTube platform are also included.

The navigability of web pages is, in general, easy and intuitive, but considering that some of the members of this group have different degrees of disability, it would be desirable to improve their accessibility. Of the associations analyzed, only two of them—dedicated to visual perception problems—allowed improving the vision of their page by increasing the size and contrast of the letters.

The analysis of these platforms highlights the work carried out by associations to disseminate information on the disease and to alleviate the educational and informative deficiencies caused by the health system; the challenge being that despite their altruistic efforts, only a small number of RD users exist. All the pages analyzed present extensive areas of content on aspects related to the clinic, diagnosis and treatment of the disease, as well as existing socio-sanitary resources—including legal aspects such as the Dependency Law and other regulations that may affect them—, even clinical guidelines for disease management.

The study shows that the majority of associations use generic social networks such as Facebook and Twitter despite the existence of specialized networks in RD such as Rare Commons, RareShare and RareConnect. This fact is corroborated when verifying that the specific networks present, simultaneously, a profile in the generic networks and in the specialized one, which leads us to believe that Facebook and Twitter allow a greater approach to the general population; which leads to associations wanting to use the more generic platforms to spread helpful information for citizens about their socio-sanitary situation. The most frequent contents are health communication and mutual support, with publications that reveal the importance of emotional support for a specific group in order to alleviate the feeling of loneliness and isolation, something that is clearly expressed in the objectives of the associations.

The results support the idea that social interaction favors patients' expectations regarding the improvement of their health condition.

Participation in virtual communities has positive benefits so that affected people can inform themselves, train and interact with other patients and with health professionals. These patients use their personal experience to empower themselves and apply this knowledge obtained to become actively involved, together with the professionals who assist them in decision-making, as well as to achieve greater self-management in the control of their disease.

The collective knowledge based on personal experiences, which arises from these virtual communities, complements the scientific-technical knowledge and could be applied in the development of plans and clinical guidelines for health action, which are better adapted to the reality experienced by these patients and their families. The cooperation between the health administration and the social network communities would allow for a holistic approach to be incorporated which in practice, is unfortunately rarely carried out, however incorporating all biopsychosocial aspects should be strived for.

Although the use of the different existing means on the Internet to obtain information produces undeniable benefits, it should be kept in mind that such information must be understandable and up-to-date. It must facilitate the patient-healthcare professional relationship and provide training in healthy habits. This is why the work of health professionals is essential to facilitate the understanding of the information obtained, as well as to resolve and clarify any doubts that may arise.

#### LIMITATIONS AND PROPOSAL FOR FUTURE INVESTIGATION

The generalization of the results is subject to certain limitations. Although the associations that are part of the sample do not represent the total of existing entities, they are useful in offering a sufficiently clear idea of how VPC with RD work and which of the Internet tools are most applicable to fulfill patients' needs for communication and information.

Exclusively analyzing open resources is a limitation regarding the knowledge of the quality and content of messages that are shared, for example in more private spaces and that could reflect other less well-

known interests of the community. It would be advisable, therefore, to analyze other models of private communication, increasingly popular, such as WhatsApp or Telegram instant messaging, which allow the creation of groups and private interaction and which can present to be very useful as a social network for this type of pathology made up of a small number of people.

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