UNIVERSITAT ROVIRA I VIRGILI

HEALTH COMMUNICATION PROCESSES IN SOCIAL MEDIA: TOWARDS A TRANSFORMATIVE INTERVENTION ON THE INFORMATION ABOUT CHRONIC PAIN

Anna Sendra Toset

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ANNA SENDRA TOSET

DOCTORAL THESIS
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Anna Sendra Toset

HEALTH COMMUNICATION PROCESSES IN SOCIAL MEDIA: TOWARDS A TRANSFORMATIVE INTERVENTION ON THE INFORMATION ABOUT CHRONIC PAIN

DOCTORAL THESIS
Supervised by Dr Jordi Farré Coma
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Tarragona 2019

UNIVERSITAT ROVIRA i VIRGILI

Dr. Jordi Farré Coma
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FAIG CONSTAR que aquest treball, titulat "Health communication processes in social media: Towards a transformative intervention on the information about chronic pain", que presenta Anna Sendra Toset per a l'obtenció del títol de Doctor, ha estat realitzat sota la meva direcció al Departament d'Estudis de Comunicació d'aquesta universitat i compleix els requeriments per optar a Menció doctor/a Internacional.

HAGO CONSTAR que el presente trabajo, titulado "Health communication processes in social media: Towards a transformative intervention on the information about chronic pain", que presenta Anna Sendra Toset para la obtención del título de Doctor, ha sido realizado bajo mi dirección en el Departamento de Estudios de Comunicación de esta universidad y cumple con los requerimientos para optar a Mención doctor/a Internacional.

I STATE that the present study, entitled "Health communication processes in social media: Towards a transformative intervention on the information about chronic pain", presented by Anna Sendra Toset for the award of the degree of Doctor, has been carried out under my supervision at the Department of Communication Studies of this university and fulfils all the requirements for being awarded the distinction of International doctor.

Tarragona, 7 January 2019

El director de la tesi doctoral
El director de la tesis doctoral
Doctoral Thesis Supervisor

Jordi Farré Coma

ACKNOWLEDGEMENTS

When you look back on your life, the only thing that matters is:
Did you spend it doing what you love, with the people you love? Were you happy?
Did you make the most of this beautiful, terrifying, messed up life?
Did you let go of all the things that held you back?
So you can hold on to what matters most

Grey's Anatomy (Season 14, Episode 11) | (Don't Fear) the Reaper

Quan estava al Festival Internacional de Cinema Fantàstic de Sitges al 2017, vaig tenir l'ocasió de poder assistir a una roda de premsa on hi havia Susan Sarandon. Allà, entre l'estira-i-arronsa de preguntes fetes per periodistes i altres cinèfils, Sarandon va fer ús de la seva condició d'estrella clàssica de Hollywood per dir a les persones que estàvem a la sala la següent frase: "vosaltres sou els guardians dels vostres somnis".

En certa manera, això és el que he fet durant els darrers anys amb aquesta tesi. La meva fortuna, però, és que en comptes d'una sola guardiana, n'he tingut una xarxa bastant àmplia que m'han ajudat a arribar fins a l'última pantalla. Qui em coneix, sap que la meva etapa doctoral ha sigut més aviat una muntanya russa d'emocions: he sigut molt feliç en molts moments, en d'altres he plorat per algun despatx o taula... però sempre ho he fet en família. Per tant, aquests són uns agraïments escrits des del cor, sobre amigues i companyes, per donar les gràcies a totes i cadascuna d'elles el suport que he rebut al llarg d'aquests últims quatre anys. Tot i així, com que sovint el meu alter ego és la Dory de la pel·lícula *Buscant a Nemo*, demano disculpes per avançat per les possibles absències.

En primer lloc, a qui haig de donar les gràcies és a en Jordi Farré, el director d'aquesta tesi. Ell ha sigut la persona que m'ha acompanyat en aquesta aventura, qui va confiar en el projecte des dels seus inicis, i qui m'ha ajudat a transformar el "tot és molt confús" en la recerca que aquí es presenta. Estic agraïda d'haver compartit batalles amb un gran professional que, tot i la meva inexperiència, sempre m'ha tractat d'igual a igual, m'ha donat llibertat en la presa de decisions, ha entès i compartit els moments durs del camí i que, en definitiva, m'ha ofert els millors consells per poder superar plegats, des de la nostra dualitat teòrico-pràctica, tots els reptes d'aquesta tesi. I, com sempre m'ha dit que això només és el punt de partida, espero poder seguir col·laborant junts en un futur no gaire llunyà.

A més d'en Jordi, al Departament d'Estudis de Comunicació (URV), altrament conegut com a DEC, hi he trobat una colla de companyes excepcionals. A banda d'aguantar estoicament el meu caràcter, totes elles també m'han ajudat a arribar a la línia de meta d'aquesta marató anomenada tesi. Per un costat, a la Iolanda Tortajada vull agrair-li especialment l'haver-me animat a fer el doctorat, i a fer-me tornar al DEC després d'una breu estada a Sescelades. Per un altre costat, al Bernat López li vull donar les gràcies per la seva honestedat, per parlar sempre amb franquesa, i també per totes les oportunitats i la confiança rebudes. Agrair, així mateix, el suport i els consells entre cafès, dinars o birres de la Laia, el David, el Josep Mª, la Cilia, l'Enric, la Sunsi, l'Arantxa, la Ile, el Paul, i el Toni. Tampoc vull deixar de mencionar a aquelles persones que hi van ser als meus inicis, com la Maria José, la Lluïsa, la Marta Arjona o la Júlia, que ara recentment ha tornat al departament. A elles m'agradaria donar-los les gràcies per fer que l'inici de tota aquesta bogeria fos molt més entretingut. D'altra banda, a la Carme i al Leandre, i més recentment, a la Maite i a la Núria, vull agrair-los la paciència i tota l'ajuda rebuda amb els tràmits inacabables que envolten la vida acadèmica.

No us penseu, però, que m'oblido de l'univers 3.21. A l'Àngels, que és la guardiana del despatx i la protectora del DEC, li vull donar les gràcies per rebre'm sempre amb un somriure, per compartir el matí dels dijous a les 7 abans d'anar a anglès, i per solucionar-me tots els dubtes i preguntes existencials que he tingut al llarg d'aquests quatre anys. A la Carlo (Charlotte), que sempre m'ha mostrat el seu suport incondicional, li vull agrair de manera especial les estones de biblio plegades durant la recta final, i per tots els viatges entre Tarragona i Reus, dues de les ciutats que compartim entre feina i vida personal. Així mateix, al Jordi Prades, la persona que completa la quadrilla del 3.21, vull donar-li les gràcies per estar sempre disposat a donar-me un cop de mà en temes de docència, i per ser un excel·lent company de Càtedra. Tot i que a vegades m'irrito quan hi ha excés de soroll, els tres saben que la meva etapa doctoral no hagués estat el mateix sense la vida i la convivència d'aquest espai de recerca. Vull aprofitar també aquestes línies per fer un agraïment especial a quatre persones del DEC. D'un costat, a la Núria Araüna vull donar-li les gràcies per la seva calidesa, i per escoltar sempre les meves dèries, aportant llum als moments on tot semblava que anava a bocafoscant, sobretot a nivell personal. D'altre costat, al Jan Gonzalo, a banda de compartir frikisme i de ser el meu proveïdor oficial de Netflix, li vull agrair de manera especial la paciència que té quan entro de manera recurrent al seu despatx a descarregar les meves frustracions diàries amb la vida, que sempre escolta amablement amb un somriure, i per deixar-me formar part del *gamification team* del DEC. A la Natàlia Lozano, *coach* i motivadora oficial d'aquesta tesi, li estaré sempre agraïda pel suport moral i professional que m'ha donat al llarg d'aquests quatre anys. De manera concreta, li vull donar les gràcies per tots els petits oasis d'oxigen que, vinguessin en forma de concerts, sopars o alguna que altra sortida en piragua, sempre m'han ajudat a desconnectar de la bombolla que envolta el procés de la tesi. Sé del cert que quan la Nat llegeixi aquestes paraules, és molt probable que digui que ella no ha fet res de tot això però, encara que no s'ho cregui, l'ajuda que m'ha ofert ha estat molt important per mi.

L'última persona del DEC a qui em queda donar-li les gràcies, però no per això és la menys important, és a la Marta Montagut. A banda de ser una companya de feina fenomenal, a nivell personal la Marta és una persona extraordinària. Sempre està disposada a donar-te un cop de mà, i mai tindré prou paraules per agrair la seva estima, ajuda i consells al llarg d'aquests quatre anys. En especial, a la Marta li vull donar les gràcies per la seva sinceritat i generositat, per mostrar-me com posar passió a tot el que faig, i per la seva empatia i capacitat observadora, que sovint han servit per aixecar els meus ànims en els moments més foscos de la tesi. Si tanco els ulls, encara em veig fent-li companyia mentre ella editava el programa del Taller de Ràdio a l'estudi de la planta 1 del Campus Catalunya fins passades les 9 de la nit. Ara, gairebé una dècada després del programa, estic agraïda també de que la Monti s'hagi convertit en una confident i amiga.

Si el tret de sortida d'aquesta tesi va començar al DEC, la preparació prèvia la vaig realitzar al grup de recerca ALGOS. És per això que en segon lloc vull donar les gràcies, d'un costat, al grup i la seva feina per inspirar-me a trobar el tema de la recerca que aquí es presenta, i d'altre costat, als seus membres per contribuir també amb la seva ajuda a la finalització d'aquesta tesi. En concret, a l'Ester vull donar-li les gràcies per cuidar de mi, i per dir sempre que sí a tots els plans d'oci; a la Cat, pels viatges en cotxe compartits, i per fer-me riure a propòsit amb la seva forma particular de dir els números; a l'Eli, per acompanyar-me a descobrir tot Copenhagen a peu tot i estar molt embarassada, i per les seves reflexions; i a l'Elena, per compartir la passió de tieta, i per tots els consells rebuts. En general, a totes elles els hi vull donar les gràcies pel suport i l'estima constants. Agrair, de la mateixa manera, l'escalf i els riures plegats entre cafès i sopars del Santi, el Pere i el Roman. Tampoc vull deixar de donar les gràcies a la Rocío, antic membre del grup, per les constants riallades cada cop que ens tocava fer un vídeo, i per deixar-me quedar a dormir a casa seva durant l'època que em vaig quedar sense cotxe mentre feia el màster. També vull donar les gràcies al Jordi Miró, cap del grup, a qui vull agrair-li sobretot la confiança rebuda durant els gairebé tres anys que vaig formar part d'ALGOS.

Thirdly, if this PhD has given me something, it's the opportunity to travel to two amazing places, which are Norway and Finland. And in both places, I met wonderful people who also helped me to end this dissertation. As for Norway, first I wanted to thank Robert for all the advice and support he has given me, and for all the incredible opportunities, especially at the end of this dissertation. Secondly, I want to thank as well Kate's support. I'm grateful to have met a PhD colleague like her, and also to consider her a friend. Even from the distance, she worries to make me laugh with memes, videos, and with her funny theories about life (and, thanks to these moments, I could maintain a balanced mental health during the last steps of the PhD process). Besides, I also want to thank her for always being willing to listen to me, for showing me Oslo, and for setting up our personal social conference program both in Lugano and Tampere.

As for Finland, place of my research stay, firstly I wanted to thank Sinikka for being an excellent mentor, for making me feel like home in Tampere, and for all the advice and support received. Apart from Sinikka, at UTA I met two amazing colleagues like Anna and Eliisa. On the one hand, I wanted to say thanks to Anna for always meeting me when she came to Tampere, for being an excellent tour guide in Helsinki, and for sharing thoughts about academia, always with a beer in our hands. On the other hand, I wanted to thank Eliisa for showing me the campus and introduce me to all the people of the department, and for sharing lunch with me every now and then at Sorsapuisto (sometimes in Anna's company too). Simultaneously, in Tampere I met marvellous people like Mikko, Nina, Pia, Sarah, Maria, Ari, Juuso, Simo, Satu, Peter, and Juha. Apart from making me feel like home, I wanted to say thanks to all of them for all the fun, parties, board games, and dinners shared together.

En quart lloc, també vull donar les gràcies a les amigues, que sempre hi són i poc a canvi demanen. Tot i que a vegades no han entès molt bé què significa fer una tesi, el seu suport ha sigut imprescindible per poder completar la pantalla final. Per un costat, tenim les de la URV, o també conegudes com a *cookies*. A la Marta li vull donar les gràcies per tots els Skypes entre Manchester i Tampere, per animar-se a compartir pis amb mi, i per escoltar tots els drames del doctorat mentre sopem plegades una de les seves delícies culinàries; a l'Ari, per contestar al telèfon sempre que ho he necessitat, per les milers de quedades on les riallades sempre n'han estat l'ingredient destacat, i per venir a celebrar l'últim aniversari abans de la tesi a Londres; a la Marina, per escoltar-me sempre, per donar els millors consells a través d'àudios eterns de WhatsApp, i per venir a Tampere i haver compartit amb mi una part de Finlàndia; a l'Anna, per tots els cafès on ens hem posat al dia; i a la Maria, per compartir els problemes de doctorat gairebé sempre amb un gelat a les mans. D'altra banda, vull agrair també el suport de la Neus que, quan era necessari, sempre hem trobat el moment per compartir unes cerveses; així com donar-li les gràcies al David, que des de la "capital del reino" sempre m'ha mostrat el seu suport incondicional. De la mateixa manera, a la Helle vull donar-li les gràcies pels dies compartits a Finlàndia, per fer que totes les coses siguin sempre més divertides, i per haver-nos conegut millor al llarg d'aquests últims anys.

Finalment, també vull agrair el suport de les persones més properes, és a dir, d'aquelles que sempre hi són encara que les coses no acabin d'anar bé del tot. Als meus pares, la Carme i l'Àngel, vull donar-los les gràcies per la paciència infinita, per la seva estima, i per lluitar i sacrificar des de sempre un nombre indeterminat de coses per fer que la meva germana i jo arribéssim el més lluny possible. A ella, a la Mireia, vull agrair-li que sempre m'hagi defensat i que, juntament amb l'Albert, sempre m'hagin ofert el seu suport (sobretot salvant diverses vegades el portàtil), i a banda d'haver-me obsequiat amb el millor regal del món quan es van convertir en pares. Al Guillem i a la Clara, els meus nebots i reines de la casa, vull donar-los les gràcies per les estones de joc compartides, que sempre m'han fet oblidar els maldecaps del procés doctoral per unes hores, i per la seva estima i amor incondicional cap a la tieta. Agrair, també, el suport de la Lídia i el Josep, sobretot per totes les vegades que m'he quedat a casa seva quan l'endemà tocava marxar corrents cap a l'aeroport. Per acabar, també vull donar les gràcies als que ja no hi són, en concret a l'àvia

Carme, una dona lluitadora que sempre va donar-m'ho tot, i perquè sé que és la persona que probablement avui estaria més orgullosa de veure'm arribar al moment final d'aquesta etapa doctoral.

Lastly, I would like to thank Anni for bringing colour into my life.

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ABSTRACT

Chronic pain is a complex condition, and patients who suffer from it have to deal on a daily basis with added problems like isolation, disbelief, or stigmatization. In this framework, social media arose as platforms where these individuals found spaces to freely express the pain they were experiencing, and where they started to form online support communities to partake of their concerns with other pain patients who were suffering from the same worrying and stressful illness. Against this background, the main objective of this research is to critically analyse the communicative processes of pain in social media both from the regular logic of health institutions and from the own perspective of chronic pain patients.

Particularly, this thesis reviews these exchanges of information on Twitter (in the case of health organizations) and on Instagram (in the case of patients). On the one hand, a total of 2474 tweets are analysed, in order to find out how these health institutions create and communicate messages about pain in these platforms. On the other hand, a sample of 350 Instagram posts is examined, with the

objective of understanding the narratives that patients use in these online environments to communicate this condition. Prior to the examination of these data, the state of the art of social media health communication policies of these organizations is scrutinised.

In both analysis, two exploratory methodologies based on studies related to social media analysis and health (in the case of pain-related institutions) and articles linked to illness narratives and uncertainty and communication (for the chronic pain patients' case study) are used. After evaluating these processes separately, the challenge must be focused on how to improve the interactions between physicians and pain patients in these platforms within the framework of social support theory (this is carried out by means of a systematic review of the literature).

Results show that pain patients are advanced users of social media and are employing actively these spaces to express creatively their pain, and differently from health institutions. On the contrary, these organizations are still in an early stage in relation to the integration and utilisation of these platforms for pain communication. Besides, in both cases patient-physician interactions in these environments are minimal. However, the underpinnings of social support theory applied to the use of social media are showing opening capabilities to be addressed in order to fill up the communicative gap between sufferers and care providers in these networked spaces. The use of technologies for the self-management of health is going to increase during the following years, and organizations need to be aware that this rising situation is boosting and reshaping the current model of health care. In the case of chronic pain, the results of this research point out that the use of these online tools could improve both the management and assessment of this condition.

Frequently, pain is lived as an invisible and poorly communicated condition. To take a constitutive approach from a communicative framework involves illuminating the "painful problematic" through new and promising avenues for research.

ACRONYMS

CDC – Centers for Disease Control and Prevention

ECDC – European Centre for Disease Prevention and Control

EU – European Union

IASP – International Association for the Study of Pain

ICT – Information and communication technologies

OECD – Organisation for Economic Co-operation and Development

WHO – World Health Organization

FIGURES[1]

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[1] Figures not included in the studies presented at the Results section.

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FOREWORD

This thesis has been developed within the patronising of the ASTERISC Communication Research Group (URV). Thanks to the help and support of their members, the group gave me the opportunity to begin this new research line on health communication and chronic pain, and to learn to do research that enhanced my skills as a researcher during the process.

Likewise, the motivation to carry out this dissertation arose from two different pathways: first, from my job as a Social Media Manager in the psychology group ALGOS Research on Pain, inside which they taught me the deep reasons why chronic pain is so significant for our society; and, second, from my father's chronic illness, which motivated me to look for new ways to deal with pain so that he could have a meaningful life with more well-being and less pain.

Particularly, this dissertation is focused on analysing the communication processes of chronic pain in social media, both from the perspective of the individuals that suffer from this condition and from the point of view of the professionals who treat and assess them. In doing that, this thesis is divided into different parts: introduction, objectives, methods, results, discussion, and conclusions (plus the final references and the appendixes at the end). In the first place, the introduction reflects on the concept of health communication, explaining firstly the particularities of these terms in a separate form, and them comparing some of the key definitions of health communication that we can find in the expert literature. Then, it provides a brief explanation of the new dynamic between physicians and patients in relation to the use of new technologies. Further on, it focuses on pain, pointing out the characteristics of this condition and discussing about the particularities of the concept of pain communication. In the final part of the introduction, it is described the importance of health 2.0 and how the use of these technologies could lead health institutions into changing the procedures through which health systems work.

Secondly, the following sections introduce the objectives of this research and an overview of the methodologies used in each study. Thirdly, the results section presents the five manuscripts included in this dissertation: a book chapter (published in *Educación, comunicación y salud: Perspectivas desde las ciencias humanas y sociales*) and four research articles (the first two studies (Study I and Study II) published in the *Revista Española de Comunicación en Salud* and the *Catalan Journal of Communication & Cultural Studies*, and the last two (Study III and Study IV) currently under a tortuous peer-review process).

Fourthly, the following section gathers a joint coherent discussion of all the studies, providing at the last instance some of the limitations of this thesis and possible future directions for further research. At the end, the work is closed up with the presentation of the conclusions, and also with the references used. Finally, at the Appendixes section, both codification tables used in Study II and Study III are collected.

1. INTRODUCTION

1.1 Defining the concept of health communication

It is an undeniable fact that health has become one of the most important priorities of the 21st century for many organizations, including the European Union[2]. Two of the main reasons of this change of paradigm are, on the one hand, the increase of the aging population and, on the other hand, the major presence of chronic diseases within our society. In this regard, one of the last reports that analyses the state of health and care in the EU stresses that "population ageing requires profound transformations in health systems" (OECD/EU, 2018, p. 14). Likewise, the number of people that uses healthcare services on a recurring basis has also been rising during the past few years. Are health systems ready to soak up this overload of patients? Which is the importance of communication within this rising dynamic? As Rimal and Lapinski (2009) argue, one of the principal factors to improve the management of healthcare is communication. If we take into consideration that this process "is at the heart of who we are as human beings" (Rimal & Lapinski,

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[2] *Health, Demographic Change and Wellbeing* is one of the main challenges of the program Horizon 2020, funded by the EU (European Commission, n.d.-a).

2009, p. 247); it is essential for health organizations to learn how to effectively communicate messages both within and outside health care environments. The branch of knowledge that studies all these processes is known as health communication.

However, this discipline can be complex to delineate for a variety of reasons. Firstly, because health communication is considered a young area of study[3] that has suffered constant and multiple changes (Wright, Sparks, & O'Hair, 2008), particularly since the irruption of digital health. Secondly, because this branch of knowledge is also a multidisciplinary field that covers from health promotion to literacy or health education (Schiavo, 2007). Thirdly, because the majority of approaches to this discipline only think about health as a message that can be transmitted in communicative processes:

> The use of the term 'health communication' […] also conveys this meaning of 'health' as a phenomenon that may be 'transmitted' through communicative processes as if it were a message. The assumption is that as long as the 'message' is sent and successfully

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[3] First appearances of the term *health communication* were around the decade of the 1960s (Du Pré, 2014).

> 'received' often enough, then the state of 'health' will be accomplished. (Lupton, 1995, p. 107)

As a consequence, although some institutions[4] do have a definition for this dual concept, health organizations still do not have a unitary explanation of what health communication is. Moreover, Torkkola (2009, p. 1) points out that this concept is usually "not analysed" sufficiently by academics. Therefore, to be complementary with this problematization, it is examined below some of the existing *health communication* definitions to see to what extent they do contemplate, or not, all the dimensions that this discipline assembles.

Nevertheless, before analysing these explanations, first we need to reflect on the meaning of the terms health and communication in a separated way. From a global health institutional perspective, the World Health Organization (WHO) defines the concept of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948, cited

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[4] In this introduction, we argue about different definitions of the term *health communication* made by health-related organizations like the European Centre for Disease Prevention and Control (ECDC) or the Centers for Disease Control and Prevention (CDC).

by WHO, n.d.-a, p. 1). Some divisions of the medical community consider this archetypical definition as controversial, because this condition of "complete health «would leave most of us unhealthy most of the time»" (Smith, 2008, cited by Huber et al., 2011, p. 1). In a world where chronic diseases are one of the main burdens of health systems, who are the ones that can achieve this desired health status?

Moreover, it is key to understand that malady can be conceptualized broadly as *disease* (health professionals approach), *illness* (patients approach), or *sickness* (social role approach) (Hoffman, 2016). From this tripartite, the WHO definition is particularly focused on the *sickness* dimension of malady. As Hoffman (2016, p. 16) points out, this approach encompasses "how a person's social role is defined or changed by social norms and institutions". Therefore, the standard for this organization is to achieve this status of "complete" health, minimizing "the role of human capacity to cope autonomously with life's ever changing physical, emotional, and social challenges and to function with fulfilment and a feeling of wellbeing with a chronic disease or disability" (Huber et al., 2011, p. 2). In other words, as stated by this apparently wide definition, those with chronic diseases are condemned to remain on the margins of society. Conceptually, the WHO description exemplifies how health-related organizations repeatedly promote a discourse where maladies have always a cure (Frank, 1995).

However, there are maladies where *disease*[5] is absent. For instance, this is the case of some illnesses[6] related to chronic pain, the focus of this dissertation. Considering the WHO description, patients that suffer from maladies like these have achieved a "complete" health status, because there is *illness* but not *disease* or *sickness*. Hence, this circumstance "represents cases that are experienced by the person as negative, but are neither recognized as *sickness* by society nor as *disease* by the medical profession" (Hoffman, 2016). Torkkola (2009) designates these individuals as *undiseased ill*, and these patients are

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[5] Sharf and Vanderford (2008) define *disease* as "organic malfunctions and pathological processes whose signs and symptoms […] can be observed and quantitatively assessed" (Sharf & Vanderford, 2008, p. 14).

[6] Fibromyalgia is the clearest example of this type of illnesses (National Health Service, 2016).

often stigmatized because they do not fit the standards set by the social norm. As it is noticed from these particularities, the definition proposed by WHO leaves uncovered both those who suffer from chronic diseases, and those –within this group– who have maladies that are not recognized by society or health systems. In both cases, communication plays a key role for generating a change, especially when the malady is only conceptualized as *illness*. At the same time, since "illness experience is an intimate part of social systems of meaning and rules for behaviour, it is […] influenced by culture" (Kleinman, Eisenberg, & Good, 2006, p. 141). Correspondingly, the meaning of "health" will also change depending on the idiosyncratic pain episodes that bias the patient's experience.

Alternatively, the Merriam-Webster Dictionary defines the term of communication as "a process by which information is exchanged between individuals through a common system of symbols, signs, or behavior" (Communication, 2018). This means that patients and health professionals, to understand each other, need to speak the same language[7]. At the same time, this "common" exchange of information will also depend on the relationship between them, according to the *principle of reciprocity* developed by Lévi-Strauss (1967, cited by Pericot, 2002). That is to say, not only professionals, organizations, and patients need to speak the same system of words for communication, but they must also recognize one another as an *effective participant* (Lévi-Strauss, 1967, cited by Pericot, 2002). Pain experiences, likewise, are shaped too by numerous cultural factors that medical and other health-related personnel should consider in these exchanges of information (Gonzalez-Polledo, 2018a).

Nonetheless, this is not what usually happens in patient-physician interactions of those affected by the pain condition. As Goldingay (2018, p. 76) argues, "for people with chronic pain, the healthcare encounter is often negative. They feel invalidated, unheard, a waste of space". In these interactions, sufferers and care providers play opposite roles, based on a hierarchical relationship marked by visual

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[7] This can be applied both at the level of patient-physician interactions and at the level of institutions (messages sent between organizations and patients).

elements such as "props and wearing costumes that signify purity, knowledge and power" (Goldingay, 2018, p. 67). On this basis, this research analyses how these relationships start to be transformed thanks to technologies like social media.

Be that as it may, not all health communication definitions consider these particularities that persist around the tricky concepts of health and communication. Firstly, Maibach and Holtgrave defined in the 1990s this discipline "as the use of communication techniques […] to (positively) influence individuals, populations, and organizations for the purpose of promoting conditions conducive to human and environmental health" (Maibach & Holtgrave, 1995, p. 219-220). In this case, the description only considers two of the three dimensions of malady (*illness* and *sickness*). In a similar vein, institutions like the European Centre for Disease Prevention and Control (ECDC) says that successful health communication practices[8] should pursue the principles of accuracy, availability, balance, consistency, evidence base, cultural competence, reach, reliability, understandability, and

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[8] The ECDC talk mostly about campaigns.

timeliness (ECDC, n.d.-a). In this case, the ECDC only takes into consideration the *sickness* dimension of malady. Moreover, in both definitions health is mainly conceived as a message (Lupton, 1995), and the exchange of information is only understood as a one-way process. Furthermore, these descriptions are focused mainly on the health promotion[9] dimension.

In the alternative, the Centers for Disease Control and Prevention (CDC) defines this concept as "the study and use of communication strategies to inform and influence decisions that enhance health" (CDC, 2011, Health Communication section, para. 2). Although this institution includes the health literacy[10] dimension, the description of health communication is still too simple. As indicated above, in addition to promotion or literacy, health communication also deals with patient-physician interactions or the utilisation of technologies

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[9] The World Health Organization (WHO) defines health promotion as "the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions" (WHO, n.d.-b, para. 1).

[10] According to the ECDC (n.d.-b, para. 1), health literacy "can be defined as the capacity that an individual has to access and effectively use health-related information, in order to promote and maintain good health".

(like apps) for the self-management of health. Simultaneously, this organization only thinks about these processes of communication without the characteristic of reciprocity, leaving unclear as well how many of the dimensions of malady are covering with this definition. Nonetheless, it is important to bear in mind that these "decisions" around health are mostly taken by patients, so is significant to point out that the CDC seems to consider the *illness* dimension of malady in their conceptualization of this discipline.

Going beyond that, it is interesting to read Schiavo's (2007) work. In her research about a holistic health communication theory, this author not only describes the concept in terms of what is indicated before, but also in connection with the policies, communities, or support:

> Health communication is a multifaceted and multidisciplinary approach to reach different audiences and share health-related information with the goal of influencing, engaging, and supporting individuals, communities, health professionals, special groups, policy makers and the public to champion, introduce, adopt, or sustain a

> behaviour, practice, or policy that will ultimately improve health outcomes. (p. 7)

Also in this case, although the definition is more elaborated than the previous ones[11], Schiavo's description still understands "health" as something that can only be transmitted, and without considering that these flows of information must be bidirectional. On this basis, Torkkola (2009, p. 4) points out that health communication "is not only a mediation or transformation of health or illness messages from the sender to the recipient. Instead, […] [it] produces health and illnesses". In relation to this assertion, one of the most complete definitions of this concept is proposed by Torkkola herself (2008, cited by Torkkola, 2009), who raises the construction of this branch of knowledge as:

> In concrete terms, health communication is communication on health and illness or their research and treatment in all areas of communication, i.e. in interpersonal, organizational and mass communication […] [that] can be based on information, emotion or experience and be both factual and fictional. (p. 5).

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[11] Schiavo's definition takes into consideration the three dimensions of malady (*disease*, *illness*, *sickness*).

Similarly to Schiavo's (2007) definition, this description is appealing because is able to take into account the three dimensions of malady: first of all, it covers the patients' approach (*illness*, talking about the emotions or experiences, which are mostly linked to this group of individuals); secondly, it contains the social role of malady (*sickness*, mentioning organizations and mass communication); and finally, it considers the health-related professionals' approach (*disease*, alluding to interpersonal communication). Additionally, under this catch-all conceptualization, health communication can be modified as well thanks to the exchanges of information about the illness. Likewise, for this author health and illness are more than a message that these individuals can convey in communicative processes. In this regard, this author adds that "what is essential in the definition is […] that the cultural understanding of health and illness is simultaneously being constructed in several areas of communication" (Torkkola, 2009, p. 5).

However, in a time where health management and the distribution of health-related information can take place through applications, web-based platforms, or social media technologies, the concept of health communication has not been revised sufficiently to include the use of these new networked resources. For instance, none of the definitions analysed above straight confronts this matter. There are two possible reasons behind this shortcoming: on the one hand, some of these descriptions were developed in a time where digital health did not exist yet (for instance, like in the 1990s definition of Maibach and Holtgrave); and, on the other hand, in more recent cases (Schiavo, 2007; Torkkola, 2009) these definitions were created when health 2.0 (which will be discussed more broadly in the next sections) was in a very early stage of progression.

All in all, taking as a reference the proposals of the latest authors examined (Schiavo, 2007; Torkkola, 2009), it is suggested a more complex and alternative definition of this discipline that already considers the possibility of using information and communication technologies (i.e. ITCs) in a renewed healthcare paradigm:

> Health communication is a multidisciplinary and versatile field of study that, using both traditional and new communication processes,

> aims to improve (through promotion, literacy, and education) (1) the interactions between all the stakeholders who take part of the health system (either citizens, patients, health professionals or organizations at different levels); and (2) the quality, efficiency, and management of health and malady (as individuals) and of the health care system (as a society).

In sum, the objective of this alternative conceptualization is to consider the sphere of ICTs, which is reflected by adding the word "new" to the definition. In addition, the description of the term also reflects the three approaches of malady, being complementary to previous definitions: *disease* (for instance, with the words "health", "organizations", or "health professionals"), *illness* (with the terms "patients", or "illness"), and *sickness* ("society", "citizens"). Finally, this reformulation tries to achieve a breakthrough in stressing that this discipline can be used (and enriched) for something more than transmitting messages of health and illness. More thoughts on this matter will be recovered and pointed out later on at the Discussion and Conclusions sections[12].

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[12] See pages 237-253 for the Discussion, and pages 255-261 for the Conclusions.

1.1.1 ICTs and the new patient-physician dynamic

The weight of ICTs in health has been progressively increasing since the mid-2000s, period inside which the concept health 2.0 surfaced for the first time (Conn, 2007). Institutions like the EU define health 2.0 or digital health as "tools and services that use information and communication technologies […] to improve prevention, diagnosis, treatment, monitoring and management of health and lifestyle" (European Commission, n.d.-b). In this regard, what it becomes a productive recommendation is that health-related institutions may also use and integrate ICTs (for instance, social media) to improve and understand health and their communication processes.

Nevertheless, the challenge is to ensure that all the stakeholders related to the health sphere participate in the practice of health communication. In relation to this matter, while several studies have shown that patients are an active part of these processes -especially concerning the use of new technologies to look for support or to enhance their communication-, health-related organizations need to discover how to work more effectively with these available tools

(Bernabeo & Holmboe, 2013; Calderón & Beltrán, 2004; Heldman, Schindelar, & Weaver III, 2013; Lovari, 2017; Thackeray, Neiger, Smith, & Van Wagenen, 2012). As the results of this thesis stress, this is still a challenge to be confronted seriously by health-related organizations (Sendra & Farré, 2016, 2017).

It is true that interactions between patients and physicians are often considered as the basis of health communication. These exchanges are drawn on mutual trust, where patients rely on practitioners to explain them their symptoms, feelings, sensations… and providers generally answer with a diagnosis that comes from an "objective" declaration. These encounters traditionally happened in face-to-face interactions (in a physician's office, for instance) or through phone calls. Nowadays, nevertheless, these interpersonal communication practices can happen as well through the Internet. Although these interactions between patients and care providers already existed before the development of health communication as a discipline (Perdiguero, 2009; Sendra, 2017), the employment of technological innovations in health (for instance, to look for information related to a malady) has provoked quantitative and qualitative changes in their relationship (Lovari, 2017; Sendra & Farré, 2017).

Apart from the expansion of ICTs, there are other elements that influence this new dynamic between patients and physicians in a negative direction. In the first instance, there is the organisational matter of the number of providers per patient. Although that in the EU the ratio of physicians per 100000 inhabitants has increased in recent years (Eurostat, 2018); a recent report on Global Strategy on Human Resources for Health has predicted a shortage, at a global level, of 18 million health workers by 2030 (WHO, 2016). Taking into consideration that aging populations are growing and growing (Haseltine, 2018), and that this group of individuals are more prone to suffer chronic illness, health systems from all over the world have started to show symptoms of unsustainability and collapse because of the overloading of patients (Haseltine, 2018). In the face of this predicted paucity, health systems are pushing to develop innovative solutions with the objective of responding to these increasing demands on management services for patients.

Related to this, it is also involved the issue of how much time health professionals spend with each patient during consultations. A recent study (Irving et al., 2017, p. 1) identified that the worldwide average varies "from 48s in Bangladesh to 22.5min in Sweden". However, most of the countries analysed in the study presented an average of 10 minutes per medical appointment (Irving et al., 2017). In cases of patients with chronic diseases, this precarious reality is especially worrying, because individuals with these conditions live time as a hidden treasure and as a torture: time for getting the right treatment, time to self-explain their symptoms, time to cope with uncertainty, time to obtain the right diagnose, etcetera. In this regard, a health professional with sufficient time to listen to them is complicated to find (Østbye et at., 2005). As a result, pain patients are unattended, on a recurring basis, by a sort of health system that is unable to fulfil positively this task.

The professionals' shortage and the lack of available time in medical appointments could be considered as two of the main reasons why patients started to use the Internet with the purpose of searching for health information and support (Scanfeld, Scanfeld, & Larson, 2010; Sendra & Farré, 2017). This practice has increased over the past few years, creating a threat for health organizations and their staff as uncontested authorities (Roland, 2018). Through this kind of behaviour, patients are becoming empowered individuals that are changing their perception, relationship and interactions with health professionals. Sosnowy (2014) denominates this uprising situation as *participatory healthcare*, because the encounters between providers and patients are no longer based on superiority. Besides, by having access and more information at their disposal, these individuals can take part more actively in the management and decision-making related with their own health.

One of the conditions where these empowering practices began to happen more regularly is pain (Gonzalez-Polledo, 2016, 2018b), the sensemaking analysis focused on this dissertation. For chronic pain patients, heath communication is not only centred on information-looking practices. The results of this dissertation on chronic pain meaningfulness underlines that their dynamics also imply support in different ways, with the formation of peer communities, and not least the challenge to break with status-quo narratives (see Results chapter for more information). In the next section it is argued how chronic pain has become one of the principal health communication questioning of the 21st century.

1.2 Pain, a global problem

Pain, in all its manifestations, must be taken into consideration as a growing health problem. Under the International Association for the Study of Pain (IASP), this condition answers to "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (IASP, 1994, cited in IASP, 2017, para. 4). Also, as stated by clinicians, this pain can be either acute or chronic[13]. In this dissertation, the focus is specifically placed on the chronic experience of pain and its gaps of communication.

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[13] Behind acute pain, there is a cause (like surgery) and its duration is no usually longer than six months, whereas chronic pain is an ongoing pain that lasts longer than six months, even if the patient recovers from the cause that provoked the pain (Cleveland Clinic, 2017).

In this regard, some studies estimate that, at present, 20 percent of the worldwide population suffers from chronic pain (Goldberg & McGee, 2011). Only in the EU, the figure of those who suffer from this condition is close to 150 million people (Eccleston, Morlion, & Wells, 2018). These numbers, however, are expected to rise due to the increase of life expectancy and the constant growth of the world population (United Nations. Department of Economic and Social Affairs, 2017). Consequently, the treatment of chronic pain is more and more expensive. In Europe, annual costs for chronic pain care are situated around 441 billion euros (Societal Impact Pain Platform, 2017). All in all, health systems from around the world are becoming unsustainable.

Similarly, the appearance of pain must be understood as a complex experience that results from many factors (Craig, 2009; Gonzalez-Polledo, 2018a; Van Hecke, Torrance, & Smith, 2013). However, not all of them can be measured and isolated through blood tests, scans or biopsies. This is the case of illnesses like fibromyalgia[14], as indicated above. Due to this fact, pain patients often experience incredulity (Newton, Southall, Raphael, Ashford, & LeMarchand, 2013) from their health professionals, as well from their loved ones. Therefore, those with chronic pain can undergo emotional distress, stigma, and isolation (Newton et al., 2013). In this regard, chronic pain management can become a black box for health professionals.

Moreover, another factor that influences pain treatment is related with the care model used by physicians. In this connection, modern medicine is mostly ruled by two paradigms. On the one hand, there is the biomedical model. As stressed by Engel (1977, p. 130), this paradigm "assumes disease to be fully accounted for by deviations from the norm of measurable biological […] variables", i.e. only the *disease* dimension of malady is considered by health professionals. However, in pain, patients' experiences are fundamental. As Martin and Peterson (2009) argue, this condition is a clear example of how

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[14] According to Wolfe et al. (2010), fibromyalgia is a syndrome that lacks from "objective physical or laboratory features or well-characterized pathologic findings" (Wolfe et al., 2010, p. 608).

certain illnesses cannot be treated or observed following the model of biomedicine:

> For those who suffer the pain and debility of chronic illnesses the process of social construction is even more relevant as it provides a set of meanings and explanations that simply cannot be accounted for by the biomedical model by which many health care professionals interpret the illness experience. (p. 579)

Conversely, Engel (1977) developed the biopsychosocial model in the 1970s. According to this paradigm, "clinicians must attend […] to the biological, psychological, and social dimensions of illness" at the same time (Borrell-Carrió, Suchman, & Epstein, 2004, p. 576). In other words, this model considers other factors besides clinical evidences (such as the economic burden or the physician-patient relationship) to evaluate illness, i.e. it takes into consideration the three dimensions of malady (*disease*, *illness*, *sickness*). A priori, this paradigm fits better the experiential reality of chronic pain patients. However, the problem is still reproduced because of the biomedical model continues in the leading of modern healthcare management (Engel, 1977; Martin & Peterson, 2009).

In the face of disbelief and inappropriate illness treatment (and in sum with the underlined reasons), patients began to use the Internet as an add-on of their pain management both to look for information related with their maladies and sharing and receiving support from other individuals[15] (Mehta & Atreja, 2015). However, as remarked previously, health-related institutions began to use these tools later than patients[16] (Thackeray et al., 2012). In consequence, within this circumstance it is created a knowledge gap between them in these digital environments: while sufferers became active users of these resources (for instance, creating peer-support groups in Facebook pages or sharing posts explaining their condition); institutions are still having problems to engage with patients in these platforms.

In this research, it is discussed how health-related organizations could address better the connection with pain patients if they were more active and creative in virtual environments. These encounters between pain sufferers and providers are confronted being analysed

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[15] As is discussed later, some of these practices are contributing to rethink health communication dilemmas.

[16] Study II discusses the possible explanation behind this fact.

from an institutional perspective (Study II), and also from the point of view of pain patients' (Study III).

1.2.1 The concept of pain communication

The complex nature of pain makes that patients feel ready to express this condition in different ways. This formulation can occur either verbally (through scales or questionnaires[17], where patients must say aloud their degree of pain based on multiple variables), or through non-verbal communication techniques (for instance, with postures of the body and facial expressions, measured as well through similar devices[18]). Pain professionals use several of these assessment tools to obtain objective measurements that allow them to evaluate the pain of the patient, and often considering only the *disease* dimension of malady. In this sense, this type of pain assessment is an example of the hard influence of the biomedical model in current health care systems. Nevertheless, there are cases where the expression of pain can also take place without and beyond the use of these instruments (Gonzalez-Polledo, 2018a).

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[17] Breivik et al. (2008).

[18] Walsh, Eccleston and Keogh (2014).

At the same time, similarly to health communication in general, this expression of pain can happen in particular at different levels: with oneself, with family and friends, and with health professionals; and, in the latter case, these expressions may be conceived to better diagnose patients' pain. In this instrumental sense, providers rely on assessment tools to define the intensity, type or duration of pain. Nonetheless, can these instruments wider capture the multiple complexities of the pain experience? Moreover, as most providers' experience time constraints, they are not often in a good condition to properly evaluate pain, precisely because the use of these tools of assessment requires in their application a lot of resources.

Contrary to these procedures, the irruption of new technologies like social media has allowed patients to communicate pain in other ways (Gonzalez-Polledo, 2016; Newhouse, Atherton, & Ziebland, 2018). For instance, these expressions can happen by sharing a text and an image on Instagram (Study III). These performative posts, where patients express their frustrations, fears or feelings, are also a substantive part of pain communication. The first book that draws on these communication practices from a social outlook consider these publications a *painscape*, a construct that is providing multiple "communicative frameworks that work outside, but also parallel to, the rating scales […] that so often characterise pain" (Tarr, 2018, p. 244).

Paradoxically, should health-related professionals use these posts in social media as a supplementary informative tool for the assessment of pain? A recent report stresses that there are more than 3 billion active social media users worldwide (Williams, 2017), and many of them are there in quality of patients. Every day, then, big amounts of health-related data[19] are generated and uploaded online. Since the treatment and assessment of pain needs to be multidisciplinary (Breivik, 2008), health institutions need to consider including this amount of data as a complementary addition to the evaluation of the pain. In this setting, the production of the data comes from the patients' own terms.

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[19] Every day, users generate "2.5 quintillion bytes of data" (Marr, 2018, para. 1) between Internet navigation, social media or digital photos, among others.

Nevertheless, this practice supposes a double-edged sword for pain sufferers. First, recurring to social media and the Internet for health-related issues can be a risk in terms of privacy or misinformation (Roland, 2018). On the contrary, some studies have shown that the use of social media by pain patients can be beneficial in terms of reducing stress or anxiety (Merolli, Gray, & Martin-Sanchez, 2013). Besides, these posts (often written from anonymity) allow chronic pain sufferers to express their concerns without be in a hurry and in a more relaxed environment than a physician's office. While these practices of communication and expression of pain have been rising among patients, health-related institutions have been progressively losing authority as those reference organizations in the health field[20] (Torkkola, 2013).

Consequently, this comparative research tries to analyse the practice of communication in social networks of both pain institutions and patients (see Results section) with the objective of making ready-to-

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[20] In fact, pain patients are one of the groups that are more active in social media platforms, according to the findings of Gonzalez-Polledo (2016, 2018b).

use recommendations for improving chronic pain management and assessment using communication.

1.3 The irruption of health 2.0

Technologies like social media are part of the sphere of health 2.0. Nevertheless, these tools are only a small part of all the innovations that are currently revolutionizing the health sector: apart from social network platforms, there are wearables, chatbots, applications, VR (virtual reality) devices, and artificial intelligence solutions that also form part of the healthcare 2.0 irruption. For instance, in the market patients can found devices like iBreve[21], a wearable to manage and relieve stress; or services like Made of Genes[22], a Spanish start-up that sequences and storages the personal genomics of any individual in the cloud. Likewise, there are also solutions addressed towards health-related organizations. This is the case of DeepAIMed[23], for example, a search engine aimed to health professionals that utilises

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[21] Draper, 2018.

[22] Made of Genes website (https://madeofgenes.life/).

[23] DeepAIMed website (https://www.deepaimed.com/).

artificial intelligence to gather the relevant medical information from all the scientific databases in the world with a single searching.

In terms of communication, these solutions mostly come through apps or web-based platforms that either facilitates patient-physician interactions and provider-provider communications or, otherwise, gives patients' access to health-related information that comes from a reliable source. Some examples of these tools are InsightMedi[24] (for physician-physician communication), KRY[25] (for interactions between patients and providers), or the app COMJuntos[26], created to improve the knowledge and access to health information of those families who have a relative –better or worse– diagnosed with a rare disease.

In either case, the possibilities in health 2.0 are multiple, and they will continue to increase in the following years as these technologies become a part of the own body and self. However, considering that

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[24] InsightMedi website (http://www.insightmedi.com/).

[25] KRY website (https://www.kry.se/en/).

[26] COMJuntos website (http://appcomjunts.es/).

health 2.0 began to develop in 2006 (Conn, 2007), health institutions still have a hard time betting on these solutions. Some of the reasons behind this fact could be budget shortages in hospitals, strict norms and regulations at an institutional level (Sendra & Farré, 2017), and matters related to ethics, entrepreneurial risks, or patients' privacy (Lupton, 2012; Roland, 2018). In this sense, Lupton (2012, p. 234-235) points out that these new devices "offer an unprecedented opportunity to monitor and measure individuals' health-related habits", which turns in "the datafication of human bodies" (Lupton & Maslen, 2017, p. 1564). Nonetheless, these new technologies also "enable access to health services, and become drivers of systemic transformations of the kinds and quality of healthcare services" (Gonzalez-Polledo, 2018b, p. 1-2). Health-related institutions, then, should not create more barriers against these type of innovations, but hold a profound debate to analyse which are the best ways to integrate these resources in a better management of digital health.

In this regard, Wright et al. (2008, p. 174) suggested that "despite the optimism over these technologies for improving healthcare, many cultural, educational, financial, and legal barriers exist that will […] shape the future of new technologies and communication". On this matter, this study involves a first deep exploration to confront with this problem in the field of chronic pain.

1.3.1 Towards a new healthcare system

In particular, this dissertation has been focused on the data created by patients and providers on social media platforms. It was decided to concentrate the analysis on these tools because marginalized groups (like those who suffer from pain) make themselves visible again when they utilise these online resources (Lovari, 2017). These users turn "to social media in order to claim new rights around data, including rights to access services and to shape discussions about the future of healthcare" (Gonzalez-Polledo, 2018b, p. 6). Taking into consideration that pain patients are one of the main groups not satisfied with the actual healthcare system, this study analyses which discussions these sufferers have in these online spaces (Study III). Besides, social media are also democratising the access of chronic pain patients to the information related to their condition (Sendra, 2017).

From an organizational perspective, the problem is to discover how to use data from social media to benefit the treatment of pain. So far, health-related organizations have used these resources mainly for health promotion (Lupton, 2012). In either case, considering that wearables are generating data that can be analysed later by a health professional, social media publications could be turned too into productive evidence[27] (in other words, useful for *disease*) for the treatment and management of pain.

When posts are shared by patients, these publications get inside the *illness* sphere of malady. Health professionals, in consequence, could improve pain treatment by including these data into the diagnosis of a patient. However, as Lupton and Maslen (2017, p. 1565) stress out, "digital technologies […] require new modes of understanding and enactment" for physicians[28]. Regarding this issue, this research realises a first proposal about how institutions can use social media

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[27] Previous studies (Merolli, Gray, Martin-Sanchez, 2016, 2018) analysed the possibility of generating evidence about health outcomes by examining the therapeutic affordances of chronic pain patients' social media use.

[28] In their study, Lupton and Maslen (2017) discussed how telemedicine is requiring the development of new sensorial skills in health professionals.

(as a tool) and their data (as evidence) to enhance the treatment of pain (Study III, Study IV). Although not everyone is participating in these online platforms, it should be recognised that these new tools could be interpreted as a part of the logical solutions needed to improve the way health systems work; either to deliver reliable pain-related information to patients', or to obtain useful knowledge and new pain assessment measures.

In front of the lack of studies that examine the relation of health institutions, pain patients, and social media with the communication of pain from the perspective of social sciences, this thesis collects an exploratory, innovative and multifarious study (constituted by several complementary publications) to enrich the meaning of both health and illness. From a communicative-centred logic, digital networks available for pain patients may further enhance either the treatment or management of this condition.

2. OBJECTIVES

Altogether, this research analyses the communicative processes of health, illness, and chronic pain both from the perspective of health-related organizations and the point of view of patients' that suffer from this condition. In order to do that, the objectives pursued are in concordance with the published works appended as the central body of this thesis.

More specifically, this research is an attempt to accomplish the next objectives:

Objective 1. To contemplate and deepen expertise about the potential of social media as a tool for the communication of pain in consonance with the expansion of the usage of the Internet and new technologies.

Objective 2. After analysing the state of the art, at a broader level, of the online health communication policy-makings of public health organizations; to study, in the context of chronic pain, how pain-related institutions create and communicate messages about this condition in social media.

Objective 3. To examine, from the patient's perspective, the narratives that these individuals utilise in these online platforms to communicate pain.

Objective 4. To explore, from a more general angle, how the principles of social support theory could improve the interactions between health institutions and patients with chronic diseases both in and through social media.

3. METHODS

This thesis includes five studies (one book chapter and four research articles): one is a preliminary point of view on the weaknesses and strengths of using social media for the communication, assessment and management of pain (Introductory book chapter); two more are systematic reviews (first, Study I realises an initial state of the art of organizations and their social media use; and, secondly, Study IV explores the relation of these tools to social support theory); and the other two conduct a content analysis of data from social media related to pain (Study II from the point of view of institutions, and Study III from the patients' perspective).

This section provides a brief overview of the methodologies used in each research paper. A more broader description of the methods followed in these studies can be recovered in the Results section.

3.1 Study I

In this first study, a systematic review of the articles related to public health organizations and social media is conducted. In particular, research papers published in English between 2004 and May 2015 are retrieved. Then, multiple key terms are identified both in the title and/or the abstract of the documents indexed in different databases (Scopus, Medline, Science Citation Index Expanded, Social Sciences Citation Index, OneFile, GALE, Taylor & Francis Online , Informa – Taylor & Francis, SciVerse ScienceDirect, SAGE Journals, Sage Publications, DOAJ, ERIC, PMC, Mary Ann Liebert, Wiley Online Library, Public Library of Science, SpringerLink, RMIT, Chongqing VIP Information Co.).

Specifically, only the studies that examine initiatives related to social media carried out by public health organizations from the point of view of health communication are collected and analysed. Further on, of each paper selected, information regarding the author/s, the initiative, the organization/s, and the content of the text is gathered. Finally, this information is assembled into a table with the objective of comparing the diverse social media initiatives of these institutions between and among them (more information on the analysis table and the list of articles included in the final selection can be expanded in Study I). For this systematic review, the recommendations of the PRISMA declaration were followed (Urrútia & Bonfill, 2010).

3.2 Study II

In Study II, a comparative content analysis of the tweets from two institutions related to chronic pain (American Pain Society (APS), Spanish Pain Society (SED)) is carried out. A total of 2474 tweets captured with the online tool Omnicity[29] are examined. The tweets analysed in this study were published from March 2013 to February 2016 in the case of the SED, and between July 2010 to February 2016 in the case of the APS.

Then, of each tweet, data regarding the content, hashtags, targets, frequency, interactivity, and pain-related information is gathered and manually coded to a table (one for each pain organization) for subsequent analysis and comparison. Afterward, the information of each pain institution is compared in an Excel file (more information regarding the creation of the matrix of analysis can be completed in Study II and in section 8.1).

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[29] Omnicity website (http://omnicity.com/ot/).

3.3 Study III

In the third study, a content analysis of Instagram posts labelled with the hashtag #chronicpain is executed. First, an initial sample of 21760 publications (extracted of the week between February 27th to March 5th 2017) is captured using the freeware Netlytic (Gruzd, 2016). Of this sample, duplicated data is removed first, and then the first sample is reduced to 350 posts following a multistage sampling strategy (Palinkas et al., 2015).

Afterward, each of these Instagram posts is classified according to 14 categories: illness narrative typology, use of the illness narrative, kind of pain (typologies), gender of the owner of the profile, kind of visual representation used (typologies), photographic frame of the persons depicted, number of comments, number of likes, pain narrative typology, use of metaphors to express illness/pain, coping strategy, references to health professionals, level of uncertainty, and level of private information sharing. This information is manually coded using an Excel file for subsequent analysis (more information on the categories used for examining the data can be found both in Study III and in section 8.2).

3.4 Study IV

In Study IV, a systematic review of the research papers related to social media, social support theory, and chronic diseases is carried out. Only articles published in English between 2004 and December 2017 are retrieved. Afterward, multiple key terms are identified both in the title and/or the abstract of the research articles indexed in the Web of Science Core Collection database (A&HCI, SSCI, CPCI-S, SCI-EXPANDED, CPCI-SSH, BKCI-S, BKCI-SHH, ESCI).

In particular, only the studies that examine the relationship between chronic diseases, social media, and social support theory are finally collected and analysed. Similarly with the Study I, from each paper selected is gathered authorial information, the number of patients' or users reached out, the chronic disease examined, and the context inside which the text is situated. The dataset is collected then into a table with the objective of examining in detail the outcomes that result from implementing social support theory to social media use, and in what extent they are translated to the management of chronic diseases (more detailed information on the analysis table and the list of papers included in the final selection can be found in Study IV). For this systematic review the guidelines of the PRISMA declaration were also followed (Urrútia & Bonfill, 2010).

4. RESULTS

Relation of the publications included in this section:

Introductory book chapter

Sendra, A. (2017). Social media and new communication strategies to pain information [Los social media y las nuevas estrategias de comunicación de la información ante el dolor]. In J. M. Comelles & E. Perdiguero-Gil (Eds.), *Educación, comunicación y salud. Perspectivas desde las ciencias humanas y sociales* (pp. 227-244). Tarragona: Publicacions URV.

Study I

Sendra, A., & Farré, J. (2016). Public health institutions and social networks: a systematic review [Las instituciones de salud pública y las redes sociales: una revisión sistemática]. *Revista Española de Comunicación en Salud*, 7 (2), 285-299.

Study II

Sendra, A., & Farré, J. (2017). Institutional pain communication via Twitter by Spanish and US pain societies: analysis of levels of use and engagement. *Catalan Journal of Communication & Cultural Studies*, 9 (1), 3-23.

Study III[30]

Sendra, A., & Farré, J. Communicating the experience of pain through social media: patients' narrative practices on Instagram. *Under review.*

Study IV

Sendra, A., Farré, J., & Vaagan, R. W. Seeking, sharing and co-creating: a systematic review of the relation between social support theory, social media use and chronic diseases. *Under review.*

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[30] Study III and Study IV are attached in the format sent to the peer-review process.

4.1 Introductory book chapter

Social media and new communication strategies to pain information

LOS SOCIAL MEDIA Y LAS NUEVAS ESTRATEGIAS DE COMUNICACIÓN DE LA INFORMACIÓN ANTE EL DOLOR[1]

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Resumen: El sistema sanitario está viviendo una revolución sin precedentes. En un entorno cada vez más digitalizado, nuevas herramientas están cambiando la forma en la que tradicionalmente hemos manejado nuestra salud. La relación médico-paciente ya no es de superioridad, sino que el enfermo cada vez es más protagonista de su salud. Los *social media* forman parte del cambio, y aquí veremos varias ideas sobre cómo podemos usarlas eficazmente para mejorar el manejo y tratamiento de pacientes con dolor.

Palabras clave: redes sociales, pacientes, comunicación del dolor, comunicación de la salud.

Social media and new communication strategies to pain information

Summary: The healthcare system is living a revolution without precedents. In a digitalized world, new tools are changing the traditional way that we have taken care of our health. Nowadays, the patient-provider relationship is no longer about superiority, but the patients are increasingly protagonists of their health. Social media are part of this change. In this chapter, we expose some ideas of how we can use them effectively to improve the management and treatment of patients with pain.

Keywords: social media, patients, pain communication, health communication.

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[1] Proyecto financiado con una Beca FI-DGR (2016FI_B 00212) de *l'Agència de Gestió d'Ajuts Universitaris i de Recerca* (AGAUR) de la *Generalitat de Catalunya*.

Comelles, Josep M. y Perdiguero-Gil, Enrique (eds.), *Educación, comunicación y salud. perspectivas desde las ciencias humanas y sociales*, Publicacions Universitat Rovira i Virgili, Tarragona, 2017, p. 227–244. ISBN: 978-84-8424-518-6. DOI: 10.17345/9788484245186

Descifrando el concepto de pain communication

La Asociación Internacional para el Estudio del Dolor (IASP) define el dolor como una experiencia sensorial y emocional desagradable, asociada a un daño tisular[2] real o potencial, o descrita en términos de dicho daño.[3] Según un estudio reciente, se estima que el 20% de la población mundial padece dolor (Goldberg, McGee, 2011). Sin embargo, aunque se trata de un problema global, el dolor sigue sin ser tratado correctamente. Aunque se atiende principalmente desde una perspectiva médica, un elemento clave en su tratamiento es la comunicación.

Según Miró (2012b: 394) el dolor es una experiencia compleja que «resulta de la interacción de múltiples factores», ya sean cognitivos, físicos, sociales, o somáticos, entre otros. Ante tal variedad de causas que se presentan, mayoritariamente, de manera conjunta, es importante que la comunicación médico-paciente sea efectiva. Si hay barreras que impiden o limitan esa interacción, el tratamiento que recibe el paciente no es el adecuado. Este intercambio de información entre los pacientes y los profesionales, que en la mayoría de los casos se produce en un entorno sanitario, se engloba dentro del concepto de *health communication* (comunicación para la salud).

El ser humano es de naturaleza curiosa, y siempre ha buscado maneras de satisfacer la necesidad de información sanitaria.[4] La comunicación «formal», destinada a proponer a la población soluciones para su salud y para responder a las enfermedades, comenzó con la propia aparición de la imprenta, aunque, por supuesto, a nivel oral y mediante manuscritos es muy anterior, y no deja de tener visos de «formalidad». A partir del siglo xx, el cine, la radio, la publicidad y la televisión analógica empezaron a jugar un papel determinante, aunque la idea de «comunicación para la salud» como área de estudio emergió a finales de los años sesenta (Du

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[2] Daño en los tejidos.

[3] *International Association for the Study of Pain (IASP). IASP Taxonomy*. Seattle [Consultada el 10/12/2016].

[4] Llamero (2015) apunta en su investigación que «para comprender las implicaciones del consumo de información sanitaria virtual nos hemos de remitir a las diferentes etapas de la medicalización de las sociedades. Este concepto hace referencia al proceso mediante el cual las profesiones médicas […] han ido adquiriendo hegemonía en la gestión de la salud y las atenciones. En el último cuarto del siglo xx los conceptos de *paciente informado* y *autonomía* comenzaron a cuestionar esta hegemonía» (Llamero, 2015: 101).

Pré, 2014),[5] y engloba «la forma en que buscamos, procesamos y compartimos» información sobre salud (Thornton, Thornton, 1992, citados en Du Pré, 2014). Desde su aparición como campo de investigación hasta el inicio del nuevo milenio, la aplicación de este concepto se reducía al análisis de la publicidad televisiva o radiofónica, la lectura de un libro o de un artículo de una revista o periódico o, simplemente al intercambio de información entre el médico y el paciente durante una consulta médica.[6] Sin embargo, a partir del año 2000[7] la situación vivió un giro radical gracias a la aparición de las nuevas tecnologías, cambiando la definición del concepto de *health communication* tal y como se entendía en el pasado.[8]

Una nueva generación, una nueva realidad

Si repasamos la cronología de la aparición de varios *gadgets* tecnológicos, observamos que el primer ordenador tal y como lo entendemos actualmente apareció en 1981, el famoso IBM Personal Computer 5150.[9] En la

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[5] Como apunta Perdiguero (2009), la comunicación para la salud no es una novedad del siglo xx o xxi, sino que existen «numerosas obras que se dedicaron a finales del siglo xix a tratar de analizar y solucionar el problema de la mortalidad infantil, para divulgar numerosos consejos que trataban de modificar lo que se consideraban errores de crianza» (Perdiguero, 2009: 61). Para Perdiguero, esta forma de trabajar «se encuadra en la nueva manera de afrontar las enfermedades que se produjo a partir del final del siglo xix en Europa y en EUA» (Perdiguero, 2009: 61).

[6] Según Perdiguero (2009), desde inicios del siglo xx «la medicina social puso en marcha diversas tecnologías de intervención que variaron las fronteras del ámbito de la salud pública. […] Se llevó a cabo un cambio en la estrategia asistencial que se cristalizó en el inicio de las campañas sanitarias y en la aparición de un nuevo dispositivo asistencial, el dispensario» (Perdiguero, 2009: 62).

[7] Fue a partir del año 2000 cuando aparecieron las primeras plataformas 2.0, con el objetivo de facilitar la interacción entre las personas que compartían intereses comunes en música, educación y películas, entre otros (Edosomwan *et alii*, 2011: 79).

[8] Según Uittenhout, «antes de la gran adopción de Internet, la gente obtenía la información sanitaria de su entorno personal o cercano» (Uittenhout, 2012: 11). Ahora, la diferencia está en que «con el uso de los *social media*, el público puede interactuar y conectar con la información suministrada preguntando dudas, o añadiendo información» (Uittenhout, 2012: 13); de manera que la información especializada está disponible donde y cuando los usuarios la demandan. Además, estos nuevos medios convierten en más accesible la experiencia de los profesionales sanitarios (Uittenhout, 2012).

[9] Alfred, Randy (2011). *Aug.12, 1981: IBM gets personal with 5150 PC. Wired*, 8 de noviembre de 2011. [Consultada el 10/12/2016].

música, la evolución vino de la mano del *discman* en 1984 con la llegada al mercado del reproductor portátil D-50 de Sony.[10] La consola de bolsillo *Game Boy* se presentó en 1989.[11] El primer *boom* de los teléfonos móviles se produjo a finales de los años 90 cuando Nokia introdujo el modelo 3210, uno de los terminales más vendidos de la historia con 160 millones de unidades.[12] Son sólo algunos ejemplos de los avances tecnológicos con los que creció la generación *millennial*[13] y que han cambiado nuestra forma de entender el mundo. Establecen un antes y un después en la forma de vivir nuestras vidas, pero todavía falta un ingrediente para comprender su efecto en la *health communication* asociado al desarrollo de la tecnología derivado del despliegue de Internet.

La conexión *wireless* y la generalización de las tarifas planas han permitido una gran penetración de la conexión a Internet en los países desarrollados. En 2015, aproximadamente el 80% de los habitantes de estos países se conectan de forma habitual,[14] permitiendo a los *millennials* y a sus predecesores (el cambio lo han liderado ellos, pero sus progenitores también participan en él) la utilización de la red no sólo como fuente de información, sino como una herramienta que complementa su estilo de vida.

Según una encuesta reciente del Instituto Nacional de Estadística, 7 de cada 10 hogares españoles dispone de conexión a Internet, y además 5 de cada 10 españoles usa la red como canal de información habitual.[15]

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[10] Gina (2015). *Flashback Friday: The Sony Discman (1984)*. *Sony Official News*, 22 de mayo de 2015. [Consultada el 10/12/2016].

[11] Nintendo España. *Game Boy. La consola de bolsillo de toda la vida*. [Consultada el 10/12/2016].

[12] Meyers (2011). *What the Incredible 70-Year Evolution of the Cell Phone*. *Business Insider*, 6 de mayo de 2011. [Consultada el 10/12/2016].

[13] *Millennial* es el término utilizado para describir «la generación nacida entre 1980 y 1995» (Ng, Schweitzer, Lyons, 2010: 281). También reciben el nombre de Generación Y, Nexters o Generación Nexus (Barnard *et alii*, 1998, Burke, Ng, 2006; Zemke *et alii*, 2000, citados en Ng, Schweitzer, Lyons, 2010), «debido a las características y los eventos que definen sus vidas (p. e., globalización, rápido avance tecnológico, crecimiento de la diversidad demográfica)» (Ng, Schweitzer, Lyons, 2010: 282).

[14] BBC News. *Internet used by 3.2 billion people in 2015*. 26 de mayo de 2015. [Consultada el 10/12/2016].

[15] Instituo Nacional de Estadística. *Encuesta sobre Equipamento y Uso de Tecnologías de Información y Comunicación en los Hogares*. Instituto Nacional de Estadística. 1 de octubre de

Centrándonos en la salud, en la última Conferencia Europea Anual de Salud Digital, celebrada en Barcelona en mayo de 2015, se comentó que 9 de cada 10 pacientes estaría dispuesto a usar herramientas digitales para cuidar de su salud.[16] Ante estos datos, no puede negarse que la información sanitaria que encontramos a través de estos canales ha adquirido una especial relevancia.

> In recent years, the widespread adoption of computers, new software programs, the Internet, and other new technologies (e.g., cellular technology, global satellite positioning chips) has led to a variety of changes in communication within the healthcare system, the ways in which people obtain health information, and the ways in which they communicate about health in daily life (Wright, Sparks, O'Hair, 2008: 12).[17]

Si a todo esto le añadimos la aparición de los denominados *social media* (redes sociales[18]), el cambio es completo. Su uso, cada vez más extenso, ha cambiado la *health communication*, especialmente en las cohortes de edades denominadas *millennials*. Se trata de una regeneración transversal sobre cómo vivimos que afecta a todos los ámbitos de nuestra existencia, más allá del concepto de *health communication*. Son personas que viven por y para la tecnología, y lo han convertido en su estilo de vida. Como ya se ha señalado, un *millennial* es aquella persona que nació entre los años 1980 y 1995 (Ng, Schweitzer, Lyons, 2010); y aunque el dato, por sí solo, es irrelevante, si le sumamos todos los avances tecnológicos gestados

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2015. [Consultada el 10/12/2016].

[16] Sendra, Anna. *El futuro de la salud digital en Europa se da cita en Barcelona*. ALGOS blog. 21 de mayo de 2015. [Consultada el 10/12/2016].

[17] «En los últimos años, la adopción generalizada de los ordenadores, los nuevos programas de software, Internet y otras nuevas tecnologías (por ejemplo, la tecnología móvil o los chips de posicionamiento global por satélite), ha propiciado una variedad de cambios en la comunicación dentro del sistema sanitario, en las formas en que las personas obtienen información sobre salud, y también en las formas en que estas personas comunican sobre salud en la vida diaria» [Traducción de la autora].

[18] Hay que diferenciar este concepto del definido por Elizabet Bott en los 50. Para ella, el término *social network* (traducido al español como «red social») describe un conjunto de relaciones sociales para las cuales no hay una frontera común (Bott, 2001). Bott, hace referencia a Barnes, otro académico que define lo siguiente respecto a las *networks*: «cada persona está en contacto con un número de personas, algunos de los cuales están directamente en contacto con los otros y algunos de los cuales no… es conveniente hablar de un campo social de este tipo como una red» (Barnes, 1954, citado en Bott, 2001: 59).

en aquella época y detallados al inicio de este apartado, el planteamiento empieza a tener sentido.

Los *millennials* han tenido parte de culpa en este cambio de paradigma: «as digital natives, students have grown up in an era of widespread use of technology, which now plays a major role in education, interpersonal communication, and the formation of social relationships» (Wells, Lehavot, Isaac, 2015: 1017).[19] Para ellos, publicar opiniones personales, experiencias o contenido en redes sociales es un comportamiento natural —han nacido con un *smartphone* en la mano—, y no les plantea ningún tipo de riesgo (Wells, Lehavot, Isaac, 2015).

La introducción de los social media en el sistema sanitario

Asimismo, los *social media* facilitan también a los profesionales sanitarios la comunicación médico-paciente.[20] A nivel general, los *social media* permiten informar, educar y empoderar a las personas sobre temas de salud; incrementar la velocidad de la información durante las emergencias sanitarias; movilizar las asociaciones comunitarias; facilitar cambios de comportamiento; recopilar datos; y comprender las percepciones del público que participa en ellos (Thackeray, Neiger, Smith *et alii*, 2012). Sin duda, se trata de herramientas que van adquiriendo importancia y, actualmente, el 40% de los consumidores de *social media* reconocen que la información sanitaria que encuentran a través de estos canales afecta la manera en que manejan y cuidan de su salud.[21] Su auge ha normalizado el concepto de *participatory patient-hood*, o a nivel más general, el de *participatory healthcare* (Sosnowy, 2014), es decir, la conocida como «salud

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[19] «Como nativos digitales, los estudiantes han crecido en una era de uso generalizado de la tecnología, que ahora juega un papel importante en la educación, la comunicación interpersonal, y en la formación de relaciones sociales». [Traducción de la autora].

[20] Mientras que los *social media* permiten a los pacientes encontrar apoyo y estar más informados (Chretien, Kind, 2013); los médicos usan las redes sociales principalmente «para leer noticias, escuchar expertos, buscar nuevos avances médicos, para hacer nuevos contactos y para conectar con otros colegas en relación con los problemas de los pacientes» (Househ, 2013: 246).

[21] Govette, Jonathan (2014). *24 Outstanding Healthcare Social Media Statistics*. LinkedIn, 28 de abril de 2014. [Consultada el 10/12/2016].

participativa».[22] Mediante estos instrumentos, los pacientes han podido crear espacios de diálogo colectivo entre iguales donde poder expresar sus sentimientos e ideas sin barreras, algo que quizá no sería posible en el entorno de una consulta médica:

> En España, […] los usuarios de la sanidad pública tenemos a veces la sensación de estar haciendo perder el tiempo al médico, de ser sus sumisos servidores y no su fuente de conocimientos e ingresos. Entramos a las consultas cohibidos, pidiendo disculpas y dispuestos a que ni nos miren. Si se entienden en la visita lo agradecemos más como un favor que como un «servicio completo» (Allué, 1996: 80).

Si lo analizamos desde la perspectiva del paciente, no es lo mismo expresarte desde la comodidad de tu casa, en un entorno que dominas y donde te sientes seguro, que hacerlo en una habitación blanca, y con una persona uniformada con la que tienes un trato cordial sentada al otro lado de una mesa (elemento que es una barrera a nivel comunicativo que protege al médico, no al paciente). Es por eso que estas nuevas herramientas nos ofrecen la posibilidad de crear «espacios importantes para las personas con enfermedad para construir comunidad, participar en el activismo, y promulgar resistencia» (Sosnowy, 2014: 316). Las redes sociales permiten que el paciente sea el protagonista, ya que participa activamente de su salud colaborando con el médico e informándose sobre su enfermedad, además de debatir con otros pacientes acerca de su problema de salud (Sosnowy, 2014). En definitiva, «the […] reason physicians and other providers should be tapping into e-health and social media is that they are one route greater patient happiness–and to a more patient-centered healthcare system» (Hawn, 2009: 367)[23]. Más felicidad del paciente es igual a más eficiencia y mejor atención sanitaria.

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[22] A finales del siglo xx, San Martín señaló que la participación se entendía como «el grado de implicación activa e informada del individuo, de los grupos y de la comunidad, en la gestión de su propia salud y de la salud de la colectividad, con el objetivo de lograr cierta autonomía, bien informada, sobre la gestión de la salud individual y comunal» (San Martín, 1984, citado en Sánchez, Ramos y Marset, 1994: 57).

[23] «La razón […] por la que los médicos y otros proveedores deben adentrarse en la salud digital y las redes sociales es que son una vía hacia una mayor felicidad del paciente-y hacia un sistema de salud más centrado en el paciente» (Traducción de la autora).

El dolor y la pain communication

La *pain communication* (esto es, la comunicación del dolor) es uno de los componentes más comunes de la experiencia del dolor que ha evolucionado con el lenguaje y las expresiones no verbales en el contexto de la sociedad humana (Hadjistavropoulos, Craig, Duck *et alii*, 2011). El dolor puede expresarse: verbalmente, o no. Sin embargo, para determinar el dolor que tiene un paciente es fundamental disponer de herramientas de evaluación:

> To capture formally information on patient's pain, a pain assessment tool is vital. The pain assessment tool should be valid, that is, there should be evidence that the tool is useful for the purpose intended, reliable and easily understood by the patient. […] We consider a range of different types of tool, including rating scales and questionnaires (Mann, Carr, 2009: 35).[24]

Desde una perspectiva histórica, el dolor es uno de los «síntomas» más comunes en la demanda de atención médica (Schappert, 1989, citado en Gureje *et alii*, 1998). Sin embargo, y a pesar de la disponibilidad de analgésicos desde hace muchos siglos (p.e., el opio y, después, analagésicos y los anestésicos),[25] los cambios en la estrategia de paliar el dolor son relativamente recientes y se asocian a dos hechos: por un lado, la formulación de la *palliative care* como estrategia para mejorar la calidad de vida —muy especialmente pensada para calmar el dolor en fases terminales—,[26] y, por otro, la necesidad de disponer de herramientas «objetivas» de evaluación del dolor[27] (tal y como se ha citado al inicio). Estas últimas tratan de me-

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[24] «Para captar información sobre el dolor del paciente, una herramienta de evaluación del dolor es de vital importancia. La herramienta de evaluación del dolor debe estar validada, esto es, debe haber evidencia que demuestre que la herramienta es útil para los fines previstos, fiable, y de fácil comprensión por parte del paciente. […] Consideramos una gama de diferentes tipos de herramientas, incluyendo las escalas de evaluación y los cuestionarios» (Traducción de la autora).

[25] Pérez-Cajaraville *et alii* (2005) señalan que la primera referencia histórica que se posee sobre el uso del opio para paliar el dolor data del año 4000 a.C.

[26] La primera definición de la denominada «medicina paliativa» apareció en 1987, y en ella se dice que esta disciplina «es el estudio y el manejo de los pacientes con enfermedades muy avanzadas para los cuales la calidad de vida es el principal foco de su cuidado» (Lewis, 2007: 121).

[27] La naturaleza del dolor complica la medición de la intensidad del mismo, y por tanto, es necesario disponer de instrumentos que transformen el *feedback* subjetivo de los pacientes

dir el dolor a partir de la impresión del propio paciente (p.e., «diga cuanto le duele de cero a diez», o «no puedo soportar este dolor»), mediante cuestionarios como la *Pain Catastrophizing Scale* (PCS) (Miró, Nieto, Huguet, 2008a) o el *Pain-Coping Questionnaire* (PCQ) (Huguet, Miró, Nieto, 2009). A nivel no verbal, el dolor puede expresarse a través de fotografías (señalando aquello que te duele, por ejemplo), posturas, movimientos o expresiones faciales (Mesko, Mellades, Christ-Libertin *et alii*, 2011; Walsh, Eccleston, Keogh, 2014). Así pues, ante tal variedad de opciones, ¿por qué no aprovechar las redes sociales como una herramienta para comunicar el dolor?

Estudios recientes demuestran que las redes sociales han transformado las narrativas del dolor (Gonzalez-Polledo, Tarr, 2014). En enfermedades crónicas, su uso ha significado una mejora del bienestar psicológico del paciente (por el hecho de manejar el estrés o la ansiedad, por ejemplo); y los ha convertido en enfermos con un rol más activo, esto es, que disponen de más información a su alcance y son más participativos en la relación con sus médicos (Merolli, Gray, Martin-Sanchez, 2013). Además, «the widespread popularity of social media also enables wider distribution of messages about pain, potentially challenging excommunication» (Gonzalez-Polledo, Tarr, 2014: 14).[28] Son pacientes que recurren cada vez más a los *social media* para expresar lo que les pasa, porque allí encuentran a personas que comparten su enfermedad y entienden su sufrimiento. Encuentran apoyo, se expresan libremente sin restricciones y les permiten construir, al margen de la consulta médica, redes de apoyo que les ayudan a seguir adelante y mejorar su bienestar.

Aun así, el uso de las redes sociales en el campo de la salud está en fase de desarrollo, y existen pocos estudios que aporten datos sobre sus beneficios.[29] Pero hay algunas iniciativas que han demostrado que funcionan, aunque su efectividad no se haya probado con el suficiente rigor científico. Es el caso de la iniciativa liderada por el Centre for

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en datos objetivos para que ese dolor pueda ser evaluado (Flaherty, 1996).

[28] «La amplia popularidad de las redes sociales permite también una amplia distribución de los mensajes sobre dolor, retando potencialmente la exclusión» (Traducción de la autora).

[29] Sin embargo, varios autores coinciden en que se necesitan más estudios para determinar si los social media mejoran realmente las prácticas de comunicación en salud (Thackeray *et alii*; 2012; Moorhead *et alii*, 2013).

Pediatric Pain Research de Canadá, llamada *It Doesn't Have to Hurt*.[30] A través del *hashtag #itdoesnthavetohurt*, el centro lanzó un debate a través de los *social media* para que todo aquel que participase aportara ideas para mejorar el manejo del dolor crónico en niños, e información sobre la evidencia de la investigación en dolor crónico infantil. La etiqueta sirvió para seguir compartiendo vídeos, imágenes, encuestas, blogs y otros tipos de contenidos sobre el dolor infantil, para que la información más actualizada llegase también a los padres de los niños que padecen dolor. *It Doesn't Have to Hurt* es una iniciativa pionera, cualificada por el propio centro como una *social media campaign*, donde padres, médicos y otros profesionales del ámbito sanitario pudieron aportar su opinión acerca del tratamiento y manejo del dolor infantil.

Las dudas que plantean estas nuevas herramientas

En los estudios citados, los *social media* son beneficiosos para la *healthcare*, ya que los pacientes se transforman en personas activas que participan, cuidan y manejan su salud. Se trata de herramientas relativamente nuevas con apenas 10 años de vida que aportan numerosas ventajas, pero también despiertan crítica: «the use of […] social media by people with serious illness to find, share, and create health information is much celebrated but rarely critiqued» (Sosnowy, 2014: 316).[31]

La principal preocupación sobre su uso en el manejo de la salud es el problema de la privacidad de los datos de los pacientes (Hawn, 2009), algo que comparten los profesionales y los afectados. Es, sin duda, una paradoja: por definición, se trata de comunidades *online*,[32] donde los usuarios comparten la información con otras personas en un espacio público donde puede ser vista por una audiencia más o menos amplia. Una vez compartida, el paciente pierde el control sobre ella y eso puede afectar a la confidencialidad médico-paciente. Esta deja de ser una relación dual y pasa a ser una relación multidireccional entre personas que padecen la misma

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[30] Centre for Pediatric Pain Research (2015). *It Doesn't Have to Hurt. Proven Pain Control for Children*. Canada. [Consultada el 10/12/2016].

[31] «El uso de […] redes sociales por parte de las personas con enfermedades graves para buscar, compartir, y crear información sobre salud es muy celebrado, pero raramente es criticado» (Traducción de la autora).

[32] (2004). *Social media*. Merriam-Webster. [Consultada el 10/12/2016].

enfermedad y que no necesariamente tienen una relación personal.[33] No debemos olvidar que las redes sociales son herramientas gratuitas donde el usuario es el «producto», y por tanto, la información es poder para las empresas que las gestionan. Divulgar opiniones acerca del cuidado del paciente a través de estas herramientas «poses greater risks than doing so in person because of social media's «invisible audience» (Wells, Lehavot, Isaac, 2015: 1017).[34] Si no quieres que algo se sepa, mejor no lo compartas a través de las redes sociales.

Más allá de la privacidad, el segundo problema está en su eficacia. Son necesarios más datos, ya que «there is very little evidence to indicate that social media are being adequately used by public health organizations […] that leverage the ability to have meaningful conversations with our audiences» (Heldman, Schindelar, Weaver III, 2013: 2).[35] Disponer de más pruebas permitiría evaluar el impacto que tiene el uso de estas herramientas en la relación médico-paciente, y en los cambios de hábito o comportamiento (Antheunis, Tates, Nieboer, 2013).

[33] Aunque los *social media* han potenciado la existencia de la relación multidireccional entre médicos, pacientes y otros actores, la relación médico-paciente nunca ha sido del todo dual. Comelles (1993: 181) apunta que en el modelo médico clásico «se delegaba el control médico y la continuidad del cuidado sobre la red social del paciente porque se reconocía la lógica cultural de las prácticas sociales existentes»; y esta relación entre médico-enfermo-red social «suponía asumir y respetar la existencia de personas entendidas a las que se recurría en las crisis de salud y que era —y son— roles especializados en las propias redes sociales». Esta relación incorporaba rituales de interacción, consejos orales y prescripciones escritas entre los miembros de la red (Comelles, 1993: 173). Así pues, de una manera u otra, la relación médico-paciente siempre ha estado mediatizada por la red social que acompaña al enfermo.

[34] «Divulgar opiniones acerca del cuidado del paciente a través de estas herramientas plantea más riesgos que hacerlo en persona debido a la «audiencia invisible» presente en las redes sociales» (Traducción de la autora).

[35] «Hay poca evidencia disponible para indicar que las redes sociales están siendo usadas adecuadamente por parte de las organizaciones de salud pública […] de manera que aprovechen la capacidad de tener conversaciones significativas con nuestro público» (Traducción de la autora).

La necesidad de una buena estrategia comunicativa

Los *social media* son espacios que «allow us to share public health information in new spaces» (Heldman, Schindelar, Weaver III, 2013: 3),[36] pero es información que no podemos compartir de cualquier manera, al menos en el caso de los profesionales. Para que sean eficaces, necesitamos una estrategia de comunicación *online* que permita planificar qué información podemos compartir con los pacientes, dónde encontrarlos, y a su vez, cómo podemos hacer que esos mensajes les lleguen correctamente. Se trata de anticiparse a las inquietudes del paciente, ya que este último seguirá acudiendo a la red para buscar información sobre aquello que le pasa. Desde la perspectiva de las instituciones hay que trabajar para que los pacientes se informen de manera eficaz, con contenidos fiables, de tal manera que la relación médico-paciente sea lo más fluida posible. A la larga, puede conseguirse que los profesionales pasen menos tiempo desmintiendo informaciones falsas o incorrectas, que debatiendo con los pacientes acerca de si un tratamiento es beneficioso o no para ellos.[37]

Según varios estudios, las redes sociales funcionan mejor cuando están integradas en una estrategia de comunicación en salud global),[38] que se debe trabajar tanto a nivel de los pacientes como desde el punto de vista de los médicos. Para que esto sea posible, las instituciones sanitarias necesitan incorporar más personal que además esté cualificado para el puesto, es decir, con experiencia en comunicación para que tenga clara cuál es la estrategia a seguir y cómo debemos usar las redes sociales para

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[36] «Los *social media* son espacios que nos permiten compartir información sobre salud pública en nuevos espacios» (Traducción de la autora).

[37] Sin embargo, tal y como sugiere Llamero (2015: 123), «con el desarrollo de la web social se han generado nuevas formas de acceso a la información que se encuentran a medio camino entre la des-intermediación y la intermediación tradicional, y esto tiene consecuencias en la generación de reputación, un atributo clave en la concesión de credibilidad». Este fenómeno Eysenbach lo ha denominado «apomediación», y se trata de «una estrategia de búsqueda de información donde la gente confía menos en expertos tradicionales y autoridades como los *gatekeepers*, pero en cambio reciben la 'guía' de apomediarios, por ejemplo, a través de procesos de filtraje colaborativo en red» (Eysenbach, 2008, cit. en Llamero, 2015: 124). De esta manera, a las instituciones les espera un doble trabajo: por un lado, contrarrestar la apomediación fuertemente arraigada, y por otro, posicionarse como la fuente de información oficial y fiable a la que los usuarios quieran acceder.

[38] Ver en Thackeray, Neiger, Smith *et alii*, (2012) y Heldman, Schindelar, Weaver III (2013).

llegar a esos pacientes que buscan información sobre salud a través de la red (Harris, Mueller, Snider *et alii*, 2013). Para participar del debate, las organizaciones deben desarrollar una estrategia comunicativa que les permita relacionarse correctamente con sus audiencias.

Es importante trabajar también desde el punto de vista del paciente. La red es un lugar muy extenso, donde es muy fácil encontrar muchas fuentes de información, y muchas de ellas de dudosa procedencia (contenido falso) o con datos sin ninguna base científica. Son fuentes a las que se accede fácilmente, y nadie les está diciendo a los pacientes que aquellos datos no son los correctos o que, directamente, aquella información es falsa. Ante esta realidad, es necesario educar a los pacientes para que dejen de acudir a fuentes de información que no son las adecuadas. Aquí, la interactividad juega un papel importante: las instituciones que están tras los *social media* deben ser organizaciones activas, que contesten a las preguntas de sus usuarios, estableciendo un diálogo bidireccional. Para algunos autores, las instituciones «should fully embrace this aspect of social media engagement and encourage quick replies» (Heldman, Schindelar, Weaver III, 2013: 7).[39] Si estas organizaciones sanitarias asumen su carácter interactivo, la información sobre salud se comprende mejor y permite conectar diversas redes entre sí, de manera que los usuarios puedan encontrar los datos que están consultando en varios formatos a la vez (Park, Rodgers, Stemmle, 2011). Además de la interactividad, hay otras formas de educar a los pacientes, como por ejemplo a través de las demostraciones o talleres prácticos de búsqueda de información en Internet, siempre teniendo en cuenta que no todos los pacientes son iguales y, por tanto, no todos tienen el mismo comportamiento navegando a través de la red. Pocas son las instituciones que usan las redes sociales de forma adecuada para interactuar con los pacientes, ya que son utilizadas más como un anexo a la página web de la organización (se publica lo mismo en los dos sitios), que como un mecanismo para mejorar el diálogo con los pacientes que van en busca de información para mejorar el cuidado de su salud.

En definitiva, «si recibiéramos otro tipo de educación para la salud se incrementarían las estadísticas de éxitos y la eficacia de las instituciones» (Allué, 1996: 112). Como herramientas, las redes sociales nos permiten aplicar otros métodos educativos para enseñar a los pacientes y a la pobla-

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[39] Las instituciones «deben aceptar plenamente este aspecto de la participación en *social media*, además de fomentar las respuestas rápidas» (Traducción de la autora).

ción en general más conocimientos sobre salud, así que en los próximos años debemos encontrar cuál es la mejor manera de usarlas para que la situación cambie para mejor.

La expansión de la health 2.0 *está por llegar*

Aunque las innovaciones tecnológicas avanzan a un ritmo vertiginoso, la expresión «salud digital» aún no forma parte de nuestro vocabulario habitual. En plena era digital, el *Mobile World Congress* sólo hace tres años que incluye en su programa un evento de *digital health*, en el cual las empresas líderes del sector tecnológico presentan innovaciones sobre el tratamiento de la salud mediante herramientas digitales.[40]

Para los pacientes, la salud digital ya es una realidad. Según el portal especializado *Doctoralia*, el 90% de los usuarios[41] de Internet lo ha usado para buscar contenidos relacionados con su salud; información que más adelante tiene un peso importante en la toma de decisiones del paciente (Scanfeld, Scanfeld, Larson, 2010). Así pues, ni los profesionales ni los otros agentes implicados (instituciones, hospitales, etc.) pueden quedarse al margen, porque estos debates en redes sociales «about public health topics are happening whether we participate or not» (Heldman, Schindelar, Weaver III, 2013: 12).[42] Aun así, se necesitan más datos para saber realmente qué efectividad tienen estos instrumentos a nivel de *engagement*, para determinar si influyen en los cambios de hábito de los pacientes (Heldman, Schindelar, Weaver III, 2013).

Según un informe elaborado por la plataforma *The App Date*, está previsto que en 2017 el 65% del mercado de la *mHealth* esté compuesto por aplicaciones que permitan monitorizar enfermedades crónicas,[43] entre otras el dolor. Si hablamos de *social media*, «chronic pain expressions […] are becoming a growing archive that can be accessed from anywhere

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[40] Digital Health & Wellness Summit. *Transforming Digital Health & Wellness through Innovation*. Barcelona, 22-25 de febrero de 2016. [Consultada el 10/12/2016].

[41] Doctoralia. *1er Informe Doctoralia sobre Salud e Internet 2015*. [Consultado el 10/12/2016].

[42] «Estos debates en redes sociales acerca de temas de salud pública están ocurriendo participemos o no» (Traducción de la autora).

[43] The App Intelligence. *Informe 50 mejores apps de salud en español.* [Consultado el 10/12/2016].

in the world» (Ernst, Parikka, 2013, citados en Gonzalez-Polledo, Tarr, 2014: 2),[44] algo que indiscutiblemente está transformando las «narrativas de la enfermedad».[45] Es importante que en futuras investigaciones se plantee el uso de los *social media* no sólo como un mero complemento al tratamiento del paciente, sino como elementos estratégicos que definen la experiencia del dolor completamente diferente a lo que se ha determinado tradicionalmente (Gonzalez-Polledo, Tarr, 2014).

Ahora es el turno de los profesionales, y son ellos los que deben coger las riendas de la *health 2.0* para transformar el sistema tal y cómo lo entendemos actualmente. Y es que los *social media* nos ofrecen la posibilidad de volver a redefinir tanto los roles de los actores que participan de la *healthcare* como el diseño del propio sistema, para convertirlo en una estructura eficiente, económica, global y segura; además de proporcionarnos nuevas herramientas para mejorar el tratamiento de los pacientes. En definitiva, se trata de un proceso de cambio en el que nadie, sea profesional, paciente o un simple usuario, puede quedarse al margen. La revolución de los *social media* es una realidad, y ha llegado para quedarse.

Bibliografía

Allué, Marta (1996). *Perder la piel*. Barcelona: Seix Barral.

Antheunis, Marjolijn L.; Tates, Kiek; Nieboer, Theodoor E. (2013). «Patients' and health professionals' use of social media in health care: Motives, barriers and expectations». *Patient Education and Counseling*, 92: 426-431.

Bott, Elizabeth (2001). *Family and social network. Roles, Norms and External Relationships in Ordinary Urban Families*. Oxford: Routledge.

Chretien, Katherine C.; Kind, Terry (2013). «Social Media and Clinical Care. Ethical, Professional, and Social Implications.» *Circulation*, 127: 1413-1421. [Consultado el 10/12/2016].

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[44] Si hablamos de *social media*, «[…] las expresiones de dolor crónico se están convirtiendo en un repositorio de archivos creciente al que se puede acceder desde cualquier parte del mundo» (Traducción de la autora).

[45] Según Hyden (1997), «el concepto «narrativa» empezó a aparecer en los estudios sobre medicina y enfermedad a principios de la década de 1980» (Hyden, 1997: 50). La narrativa es «una de nuestras formas más poderosas de expresar el sufrimiento y sus experiencias relacionadas» (Hyden, 1997: 49).

Comelles, Josep M. (1993). «La utopía de la atención integral en salud. Autoatención, práctica médica y asistencia primaria». *Revisiones en Salud Pública*, 3: 169-192.

Du Pré, Athena (2014). *Communicating About Health. Current Issues and Perspectives*. Nueva York: Oxford University Press.

Edosomwan, Simeon; Prakasan, Sitalaskshmi K.; Kouame, Doriane *et alii* (2011). «The History of Social Media and its Impact on Business.» *The Journal of Applied Management and Entrepreneurship*, 16(3): 79-91. [Consultado el 10/12/2016].

Eysenbach, Gunther (2008). «Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness». *Journal of Medical Internet Research*, 10(3): e22. [Consultado el 10/12/2016].

Flaherty, Stephen A. (1996). «Pain measurement tools for clinical practice and research». *Journal of the American Association of Nurse Anesthetists*, 64(2): 133-140.

Gureje, Oye; Von Korff, Michael; Simon, Gregory E.; Gater, Richard (1998). «Persistent Pain and Well-being. A World Health Organization Study in Primary Care». *The Journal of the American Medical Association*, 280(2): 147-151.

Goldberg, Daniel S.; McGee, Summer, J. (2011). «Pain as a global public health priority». *BMC Public Health*, 11: 770. [Consultado el 10/12/2016].

Gonzalez-Polledo, Elena; Tarr, Jen (2014). «The thing about pain: The remaking of illness narratives in chronic pain expressions on social media.» *New Media & Society*, 1-19. [Consultado el 10/12/2016].

Hadjistavropoulos, Thomas; Craig, Kenneth D.; Duck, Steve, *et alii* (2011). «A Biopsychosocial Formulation of Pain Communication.» *Psychological Bulletin*, 137(6): 910-939.

Hawn, Carleen (2009). «Take Two Aspirin and Tweet Me in the Morning: How Twitter, Facebook, and Other Social Media are Reshaping Health Care.» *Health Affairs*, 28(2): 361-368. [Consultado el 10/12/2016].

Harris, Jenine K.; Mueller, Nancy L.; Snider, Doneisha; Haire-Joshu, Debra (2013). «Local Health Deparment Use of Twitter to Disseminate Diabetes Information, United States.» *Preventing Chronic Disease*, 10: e70. [Consultado el 10/12/2016].

Heldman, Amy B.; Schindelar, Jessica y Weaver III, James B. (2013). «Social Media Engagement and Public Health Communication:

Implications for Public Health Organizations Being Truly "Social".» *Public Health Reviews*, 35(1): 1-18. [Consultado el 10/12/2016].

Househ, Mowafa (2013). «The Use of Social Media in Healthcare: Organizational, Clinical, and Patient Perspectives.» En: Courtney, Karen L.; Shabestari Omid; Kuo, Alex (eds.), *Enabling Health and Healthcare through ICT. Available, Tailored and Closer*. Amsterdam: IOS Press BV, 244-248.

Huguet, Anna, Miró, Jordi; Nieto, Rubén (2009). «The factor structure and factorial invariance of the Pain-Coping Questionnaire across age: evidence from community-based samples of children and adults.» *European Journal of Pain*, 13(8): 879-889.

Hyden, Lars-Christer (1997). «Illness and narrative.» *Sociology of Health & Illness*, 19 (1): 48-69.

Lewis, Milton J. (2007). *Medicine and Care of the Dying: A Modern History*. Nueva York: Oxford University Press.

Llamero, Lluïsa. (2015). *La credibilitat connectada. Pràctiques i representacions discursives de les audiències d'internet en els camps de la salut, l'economia i el turisme.* Tesis de Doctorado. Tarragona: Universitat Rovira i Virgili. [Consultada el 10/12/2016].

Mann, Eileen M.; Carr, Eloise C. J. (2009). *Pain. Creative approaches to effective management*. Nueva York: Palgrave Macmillan.

Merolli, Mark, Gray, Kathleen; Martin-Sanchez, Fernando (2013). «Developing a Framework to Generate Evidence of Health Outcomes from Social Media Use in Chronic Disease Management.» *Medicine 2.0*, 2(2): e3. [Consultado el 10/12/2016].

Mesko, Phyllis J., Elliades, Aris Beoglos, Christ-Libertin, Cheryl y Shelestak, Debra (2011). «Use of Picture Communication Aids to Assess Pain Location in Pediatric Postoperative Patients.» *Journal of Perianesthesia Nursing*, 26 (6): 395-404.

Miró, Jordi, Nieto, Rubén y Huguet, Anna (2008a). «The Catalan Version of the Pain Catastrophizing Scale: a useful instrument to assess catastrophic thinking in whiplash patients.» *The Journal of Pain*, 9(5): 397-406.

Miró, Jordi (2012b). «Evaluación de la intensidad del dolor en el paciente con cáncer.» *Psicooncología*, 9(2-3), 393-401. [Consultado el 10/12/2016].

Moorhead, S. Anne; Hazlett, Diane E.; Harrison, Laura *et alii* (2013). «A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication.» *Journal of Medical Internet Research*, 15 (4): e85. [Consultado el 10/12/2016].

Ng, Eddy S.W.; Schweitzer, Linda; Lyons, Sean T. (2010). «New Generation, Great Expectations: A Field Study of the Millennial Generation.» *Journal of Business and Psychology*, 25(2): 281-292.

Park, Hyojung; Rodgers, Shelly; Stemmle, Jon (2011). «Health Organizations' use of Facebook for Health Advertising and Promotion.» *Journal of Interactive Advertsing*, 12(1): 62-77.

Perdiguero, Enrique (2009). «La salut a través dels mitjans. Propaganda sanitària institucional en l'Espanya dels anys vint i trenta del segle xx.» *Mètode*, 59: 61-69.

Pérez-Cajaraville, J., Abejón, D., Ortiz, J. R. y Pérez, J. R. (2005). «El dolor y su tratamiento a través de la historia.» *Revista de la Sociedad Española del Dolor*, 12(6): 373-384. [Consultado el 10/12/2016].

Sánchez, Antonio; Ramos, Elvira; Marset, Pedro (1994). *La actitud participativa en salud: entre la teoría y la práctica*. Murcia: Secretariado de Publicaciones de la Universidad de Murcia.

Scanfeld, Daniel; Scanfeld, Vanessa; Larson, Elaine L. (2010). «Dissemination of health information through social networks: Twitter and antibiotics.» *American Journal of Infection Control*, 38 (3): 182-188. [Consultado el 10/12/2016].

Sosnowy, Collette (2014). «Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise.» *Societies*, 4, 316-329. [Consultado el 10/12/2016].

Thackeray, Rosemary; Neiger, Brad L.; Smith, Amanda K.;Van Wagenen, Sarah B. (2012). «Adoption and use of social media among public health departments.» *BMC Public Health*, 12: 242. [Consultado el 10/12/2016].

Uittenhout, Herre (2012). *The use and effect of social media in health communication about common Head Lice*. Twente: University of Twente.

Walsh, Joseph; Eccleston, Christopher; Keogh, Edmund (2014). «Pain communication through body posture: the development and validation of a stimulus set.» *Pain*, 155(11): 2282-2290.

Wells, Deva M.; Lehavot, Keren; Isaac, Margaret L. (2015). «Sounding Off on Social Media: The Ethics of Patient Storytelling in the Modern Era.» *Academic Medicine*, 90(8): 1015-1019.

Wright, Kevin B.; Sparks, Lisa; O'Hair, H. Dan (2008). *Health communication in the 21st century*. Oxford: Blackwell Publishing.

4.2 Study I

Public health institutions and social networks: a systematic review

Revisiones

Las instituciones de salud pública y las redes sociales: una revisión sistemática

Public health institutions and social networks: a systematic review

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Resumen

Introducción. Esta revisión surge de la necesidad de cuantificar con datos el uso y eficacia de la comunicación sanitaria a través de las redes sociales por parte de las instituciones relacionadas con la salud. **Objetivos.** Con este estudio se quiere ofrecer una aproximación al estado actual de las políticas online de comunicación en salud de las instituciones públicas; para determinar (1) qué estrategias han funcionado y cómo se pueden mejorar, (2) cuáles son las redes más utilizadas, y (3) de qué manera se puede enriquecer su contenido. **Material y método.** Para este estudio se aplicó la metodología de la revisión sistemática. Sólo han sido incluidos los artículos *peer-reviewed* publicados en inglés entre los años 2004 y 2015. **Resultados.** De 153 registros encontrados, sólo 13 cumplen los criterios de inclusión definidos para este estudio. Aunque las instituciones usan las redes sociales como herramientas de promoción de la salud; éstas se emplean de manera unidireccional, su contenido es poco interactivo y están dirigidas por personal no cualificado. **Conclusiones.** Pese a que las redes sociales están en crecimiento y forman parte de las estrategias de comunicación de las instituciones públicas, se necesitan más estudios para determinar el alcance y efectividad de estas herramientas.

Palabras clave: Salud, comunicación, redes sociales, estrategias, instituciones publicas

Abstract

Introduction. This review arises from the necessity to quantify with data the use and effectiveness of health communication through social networks by institutions related to the health field. **Objectives.** The overall objective of this study is to provide a first approximation of the current state of online health communication policies of public institutions; to determine (1) which strategies have worked and how they can be improved, (2) which social networks are the most used, and (3) how they can create more engaging content to users. **Methodology.** For this study, the systematic review methodology was applied. They have been included only peer-reviewed articles published in English between 2004 and 2015. **Results.** 153 records were found in the search, and only 13 met the inclusion criteria defined for this study. Although institutions use social networks as health promotion tools; there is no interactive content, there is no two way communication between the institutions and the users, and the staff behind the profiles are not communication-related. **Conclusions.** Despite the fact social networks are growing and becoming part of the communication strategies of public institutions, more studies are needed to determine the extent and effectiveness of these tools.

Keywords: Health, communication, social networks, strategies, public institutions

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Introducción

En los últimos años, la popularidad de sitios como Facebook, Twitter o YouTube no ha parado de crecer entre la población (Duggan, Ellison, Lampe, Lenhart & Madden, 2015). Aunque la primera red social (Facebook) apareció en 2004, no fue hasta el nacimiento de Twitter cuatro años más tarde cuando las redes sociales empezaron a tener peso entre sus usuarios. En un entorno cada vez más digitalizado, la mayoría de la población consulta y comparte gran parte de la información en la red, incluida la información sanitaria.

Sólo en Estados Unidos, el 72% de los usuarios de internet ha reconocido que ha consultado información sanitaria en la red durante el último año, según un estudio reciente (Pew Research Center, 2012). Además, otro estudio (Scanfeld, Scanfeld & Larson, 2010) destaca que el 60% de los e-pacientes han constatado que sus consultas sobre información sanitaria en la red han tenido un peso importante en las decisiones sobre su salud. Ante este escenario, es importante que las instituciones públicas sean conscientes de esta realidad, y empiecen a incorporar las redes sociales e internet en sus estrategias de comunicación con la población.

Thackeray, Neiger, Smith y Van Wagenen (2012) numeraron en su estudio qué ventajas ofrece, en el campo de la salud pública, el uso de las redes sociales: estas permiten (1) informar, educar y empoderar a las personas sobre temas de salud; (2) incrementar la velocidad de la información durante las emergencias sanitarias; (3) movilizar las asociaciones comunitarias; (4) facilitar cambios de comportamiento; (5) recopilar datos; y, finalmente, (6) comprender las percepciones del público.

No se puede negar que gracias a la aparición de las redes sociales y otras herramientas 2.0, la relación médico-paciente ha experimentado un cambio importante (Hawn, 2009). Además, la aparición de este tipo de tecnologías hace que la salud mejore en seguridad, calidad y eficiencia (Chopra & McMahon Jr., 2011). Según una encuesta reciente, el 40% de los consumidores de redes sociales ha reconocido que la información sanitaria que encuentran a través de esos canales afecta la manera en que manejan y cuidan de su salud (Govette, 2014). Sin embargo, el uso de estas herramientas también plantea numerosas dudas.

Como comenta Hawn (2009) en su estudio, en los últimos años ha crecido la preocupación hacia la privacidad del paciente. Las redes sociales, por definición, son comunidades online donde los usuarios comparten mayoritariamente información e ideas con otras personas (Social Media, 2015), y por tanto, se trata de un espacio semipúblico donde tu información es vista y leída por un grupo importante de personas. Por ejemplo, en 2009 se detectó en Estados Unidos que el 13% de los estudiantes de medicina compartía información sanitaria sensible de sus pacientes en blogs o redes sociales personales (HIMSS Privacy & Security Committee, 2013). ¿A quién pertenecen esos datos? Ya no se trata de una relación bidireccional entre el médico y el paciente, sino que se transforma en una relación multidireccional entre personas que padecen la misma dolencia.

En la segunda década de los 2000, Eysenbach (2011) bautizó esta nueva dimensión comunicativa como *infodemiology*. Este concepto teórico hace referencia a “la ciencia de la distribución y los factores determinantes de la información en un medio electrónico, específicamente en Internet, con el objetivo final de informar sobre salud pública y políticas públicas” (trad. a., Eysenbach, 2011: S154). Esta teoría permite, entre otras aplicaciones, detectar y cuantificar diferencias en la información sanitaria disponible en la red. Ante la gran cantidad de *infodemiology* a nuestro alcance, las instituciones deben establecer normativas que limiten qué tipo de información se puede compartir, y cómo debemos compartirla sin invadir la intimidad de los pacientes.

En este sentido, uno de los organismos pioneros fue el Centers for Disease Control and Prevention (CDC) de Estados Unidos, que en el año 2010 publicó la primera versión de su kit de herramientas en redes sociales del comunicador de salud (*The Health Communicator’s Social Media Toolkit*, Centers for Disease Control and Prevention, 2015), dirigido a los profesionales del ámbito sanitario. No obstante, el CDC es una de las pocas instituciones que ha trabajado para incorporar las redes sociales a su estrategia de comunicación, y citando los datos anteriores, otras administraciones deberían plantearse seguir su ejemplo.

Objetivos

El objetivo general de este artículo es ofrecer una visión general del estado actual de las políticas de comunicación en salud en redes sociales de las instituciones públicas. Para hacerlo, se ha realizado una revisión sistemática de los ejemplos e iniciativas que se pueden encontrar de comunicación en salud en redes sociales llevadas a cabo por instituciones públicas, esto es, gubernamentales. Los objetivos específicos de esta revisión son: (1) determinar qué iniciativas y estrategias han funcionado comunicativamente, (2) cómo se deben mejorar en un futuro, (3) cuáles son las redes sociales más utilizadas, (4) de qué manera se pueden crear contenidos más atractivos hacia los usuarios, y (5) descubrir otros aspectos adicionales que conlleven estas iniciativas.

Finalmente, las hipótesis planteadas son, por un lado, que (a) existen pocas iniciativas de comunicación disponibles (con datos y estudios) realizadas por las instituciones de salud pública, y por otro, que (b) entre las encontradas, pocas están respaldadas científicamente.

Material y métodos

Para esta revisión, se siguieron las indicaciones e instrucciones marcadas por la declaración PRISMA de mejora de publicación de revisiones sistemáticas y metaanálisis (Urrútia & Bonfill, 2010). Sólo han sido incluidos los artículos *peer-reviewed* publicados en inglés entre el año 2004 (el nacimiento de la red social Facebook [Phillips, 2007]) y el mes de mayo de 2015, utilizando los términos de búsqueda (“social (media OR network)” OR facebook OR twitter) AND (health).

Los datos para esta revisión fueron identificados en búsquedas de las bases de datos científicas especificadas en la tabla 1, las cuales devolvieron 140 registros. Además, se consultaron referencias de artículos relevantes, que añadieron 13 registros más a la revisión, dejando un total de 153 registros a analizar. Tal y como se detalla en la figura 1, en una primera fase se eliminaron los registros duplicados (30), reduciendo a 123 los registros seleccionados para el análisis.

BASES DE DATOS CIENTÍFICAS
Scopus (Elsevier)
Medline (National Library of Medicine)
Science Citation Index Expanded (Web of Science)
Social Sciences Citation Index (Web of Science)
OneFile (GALE)
Health Reference Center Academic (GALE)
Taylor & Francis Online – Journals
Informa – Taylor & Francis (CrossRef)
SciVerse ScienceDirect (Elsevier)
Sage Publications (CrossRef)
SAGE Journals
Directory of Open Access Journals (DOAJ)
ERIC (U.S. Dept. of Education)
PMC (PubMed Central)
Mary Ann Liebert (CrossRef)
Wiley Online Library
SpringerLink
Public Library of Science (CrossRef)
Informit Health (RMIT)
Chongqing VIP Information Co.

Tabla 1: Bases de datos científicas consultadas para esta revisión

A continuación, los registros seleccionados se examinaron individualmente para determinar si cumplían o no con los criterios de inclusión definidos para este estudio. En esta segunda fase, 77 registros fueron excluidos por diferentes motivos (no estar relacionados con la administración, no estar relacionados con el objeto de estudio, proceder de revistas sin proceso *peer-review*, o ser *abstracts* de congresos u otros formatos diferentes al artículo científico). Al acabar esta segunda fase, 46 registros seguían aún en el proceso de revisión sistemática.

Estos 46 estudios pasaron por un segundo análisis individual (en este caso, leyendo el texto completo de los artículos) para decidir si finalmente se incluían en la síntesis cualitativa. En esta tercera fase, 33 artículos a texto completo fueron eliminados por diferentes razones (ser iniciativas del sector privado, no estar relacionados con la administración o las redes sociales, ser estudios generalistas, ser cartas al editor u otros formatos diferentes al artículo científico, o tratarse de supuestos prácticos). Una vez finalizado el segundo proceso de análisis, solo 13 artículos que cumplían con los criterios de inclusión definidos para este estudio fueron incluidos en la síntesis cualitativa.

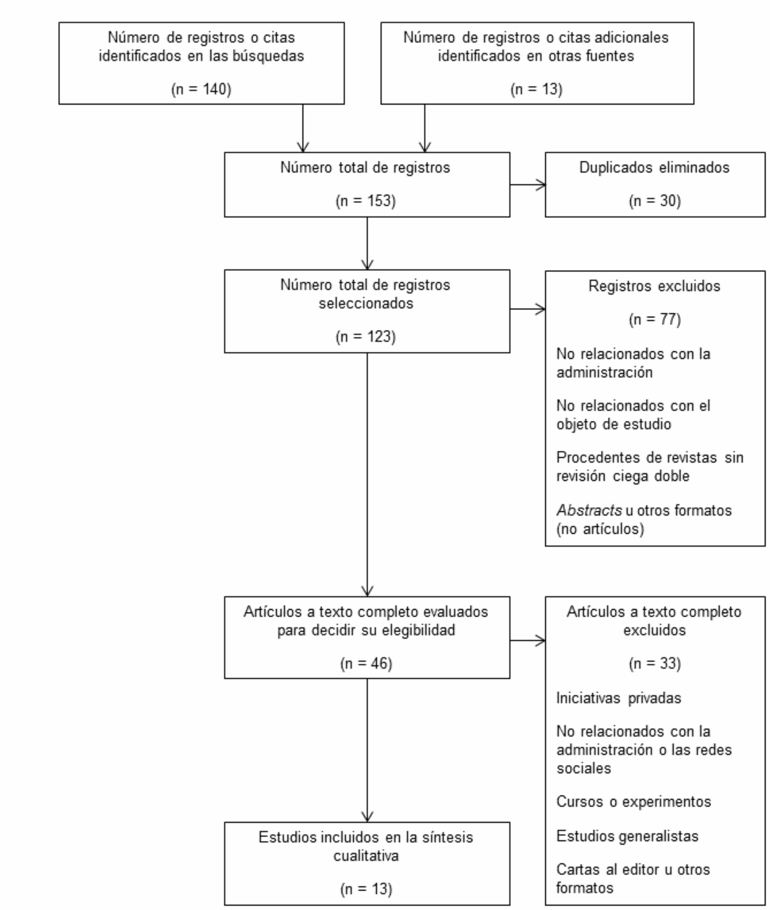

Figura 1: Diagrama de flujo de la información a través de las diferentes fases de la revisión sistemática

Resultados

Aunque existen muchas iniciativas relacionadas con la información sanitaria y la promoción de la salud a través de las redes sociales, existen pocos estudios que reflejen con datos la efectividad de las mismas. La tabla 2 congrega los 13 análisis recogidos en la síntesis cualitativa, todos ellos estudios vinculados con las instituciones públicas (ya sean asociaciones o departamentos de salud de diferentes gobiernos).

Autor/es y año	Nombre de la iniciativa	Características del estudio	Problema a resolver	Población a la que se dirige la iniciativa	Idioma	Institución que promueve la iniciativa	Red social utilizada
Anderson, Gleeson, Rissel, Wen & Bedford (2014)	Iniciativa sin nombre	Análisis del hashtag y de la cuenta oficial de la conferencia para determinar sobre qué temas se hablaba en ella y quién hablaba de ellos. Se recogieron 748 tweets bajo el hashtag #AHPA2013.	Demostrar el uso de Twitter como herramienta de promoción de congresos de salud.	Iniciativa dirigida tanto a población específica (los asistentes e interesados en la temática de la conferencia) como a población general	Inglés	Australian Health Promotion Association (AHPA)	Twitter
Bullen (2013)	MStyle Photo Booth	Los participantes se fotografiaban de manera anónima con su mensaje de salud favorito, para luego subir las fotos a la página de Facebook de la campaña (se consiguieron 15.000 impactos).	Usar fotografías en Facebook para promocionar mensajes de salud pública positivos, con el objetivo de tener relaciones sexuales más seguras.	Destinado a los hombres que tienen sexo con hombres	Camboyano (Khmer)	Cambodia Health Education Media Service	Facebook
Fallon & Schmalzried (2013)	Iniciativa sin nombre	Hay 1970 páginas de LHDs (Local Health Departments) activas, y sólo 458 tienen muro de Facebook (un 23%). Sólo 208 pueden establecer una comunicación bidireccional (un 45%), y únicamente 25 de ellos mostraron intención de comunicarse bidireccionalmente.	Investigar si los LHDs utilizan Facebook para comunicarse con el público durante situaciones de emergencia sanitaria (o si tenían intención de hacerlo en un futuro).	Población general	Inglés	Local Health Departments (LHDs) de Estados Unidos	Facebook
Harris, Mueller, Snider & Haire-Joshu (2013)	Iniciativa sin nombre	Hay 217 cuentas de Twitter de LHDs, y sólo 126 compartieron alguna vez información sobre diabetes (1024 tweets, con una media de 3 tweets por cuenta).	Analizar cómo los LHDs usan Twitter para informar y educar a la población de Estados Unidos sobre diabetes.	Dirigido a población general y a población que padece diabetes (junto con sus amigos y familiares)	Inglés	Local Health Departments (LHDs) de Estados Unidos	Twitter
Harris, Mueller, Snider (2013b)	Iniciativa sin nombre	Existen 2565 LHDs en Estados Unidos (24% tiene cuenta en Facebook, un	Determinar si los LHDs usan Facebook y Twitter como	Población general	Inglés	Local Health Departments (LHDs) de Estados	Facebook y Twitter

		8% perfil en Twitter, y un 7% tiene cuentas en ambas redes sociales). A más población, cuentas con más seguidores, innovación e interacción.	parte de su estrategia de comunicación para difundir información sanitaria de interés para la salud pública.			Unidos	
Hunter et al. (2014)	Iniciativa sin nombre	Los hombres que tienen sexo con hombres tienden a buscar pareja sexual a través de internet. Se identificaron 55 individuos (17 positivos en sífilis), y 5 de ellos formaron parte del grupo de contactos a través de Facebook.	Usar Facebook para identificar, enlazar y notificar a los individuos afectados de sífilis dentro de un grupo de contactos (cuantificarlos).	Destinado a los hombres que tienen sexo con hombres de Milwaukee (especialmente de raza negra)	Inglés	City of Milwaukee Health Department (MHD)	Facebook
Naditz (2009)	Iniciativa sin nombre	Gracias al uso de redes sociales, el MHS aumentó las visitas de su web (un incremento de miles por mes). Antes, la página sólo era visitada por un 8% del grupo de 1,4 millones de jóvenes de 18 a 24 años en servicio militar activo.	Utilizar las redes sociales para que los jóvenes de 18 a 24 años empiecen a usar los sistemas de información sanitaria del MHS.	Iniciativa dirigida a jóvenes de 18 a 24 años	Inglés	Military Health System (MHS) de Estados Unidos	Twitter, MySpace, Facebook y YouTube
Pandey, Patni, Singh, Sood & Singh (2010)	Iniciativa sin nombre	Se identificaron 142 vídeos con información relevante sobre el virus H1N1, la mayoría subidos por el Centers for Disease Control and Prevention (CDC).	Analizar el uso efectivo de YouTube como canal de información durante el inicio de una emergencia.	Población general	Inglés	Centers for Disease Control and Prevention (CDC) de Estados Unidos	YouTube
Park, Rodgers & Stemmle (2011)	Iniciativa sin nombre	Análisis del uso de Facebook con fines publicitarios por parte de las *health organizations*. Se examina el tipo de contenido publicado, el formato utilizado, y si se integran otras RRSS en las publicaciones.	Analizar cómo las organizaciones de salud utilizan las redes sociales para propósitos publicitarios.	Población general	Inglés	Health organizations (CDC, NIH and others).	Facebook

Park, Rodgers & Stemmle (2013)	Iniciativa sin nombre	Estudio sobre la alfabetización de la salud en Twitter por parte de las instituciones (571 tweets analizados). La mayoría organiza la información sobre salud disponible en la red para los otros usuarios, usando frases cortas y un lenguaje simple.	Analizar cómo las instituciones relacionadas con la salud utilizan Twitter para promover la alfabetización de la salud.	Población general	Inglés	Health-related organizations de Estados Unidos	Twitter
Syred, Naidoo, Woodhall & Baraitser (2014)	Say Yes to the Test	Campaña de educación sobre la clamidia en Facebook. 576 usuarios interactuaron con la página 888 veces, generando 508 posts y 380 comentarios. La página recibió 191.072 visitas.	Animar a los jóvenes ingleses a someterse a una prueba sobre ETS (clamidia) a través de una campaña en Facebook.	Iniciativa dirigida a población joven (hombres y mujeres) de entre 15 y 24 años	Inglés	English Department of Health, Health Protection Agency (PHE)	Facebook
Thackeray, Neiger, Smith & Van Wagenen (2012)	Iniciativa sin nombre	Sólo el 60% de los SHDs usan RRSS (sobre todo Twitter, Facebook y YouTube). En general hay poca interacción con los usuarios, y los perfiles tienen pocos seguidores (media de 1 post por día).	Analizar cómo los SHDs han adoptado las RRSS a su estrategia de comunicación en salud.	Población general	Inglés	State Public Health Departments (SHDs) de Estados Unidos	Twitter, Facebook, YouTube, Flickr
Trueland (2014)	NHS Change Day	Campaña a través de Twitter (NHS Change Day) que pretende dar la oportunidad a las personas (enfermeras y profesionales sanitarios, principalmente) de opinar públicamente sobre si algo del sistema sanitario debe cambiar (189.000 promesas registradas en la primera edición del año 2013).	Explicar los resultados de esta particular iniciativa en RRSS, en donde una conversación de Twitter entre profesionales acaba provocando cambios reales en el sistema sanitario a través de 'pledges' o promesas.	Iniciativa que inicialmente se dirigía solamente a público especializado (enfermeras y personal sanitario), pero que actualmente se dirige a toda la población	Inglés	National Health Service (NHS) del Reino Unido	Twitter

Tabla 2: Iniciativas reportadas en las bases de datos científicas

Como se puede comprobar en el citado cuadro, la mayoría de las iniciativas se produjeron en países de habla inglesa (92.3%). A su vez, se han identificado dos tipos de estudio: por un lado, la gran mayoría analizan cómo las organizaciones utilizan las redes sociales en sus estrategias de comunicación a la hora de informar sobre salud (76.9%); mientras que por otro lado, el resto analiza el éxito o fracaso de realizar campañas o iniciativas concretas de promoción de la salud a través de las redes sociales (23.1%).

En cuanto a clasificación por países donde se han llevado a cabo estos estudios o análisis, gran parte de ellos se han desarrollado en Estados Unidos (69.2%). El resto, dos se han producido en el Reino Unido (15.4%); uno en Australia (7.7%) y uno en Camboya (7.7%). Si se miran redes sociales en concreto, Facebook es la herramienta que aparece mencionada en más estudios (61.5%), seguida de Twitter, que es la segunda más analizada (53.8%). En dos de los estudios también se analiza el potencial de YouTube (15.4%), y finalmente, también se menciona a MySpace (7.7%) y a Flickr (7.7%). Destacar que los porcentajes expresados en la segunda parte de este párrafo son respecto al total de los estudios (n = 13), por tanto, la suma de todos los porcentajes es superior al 100%.

Respecto a la temática de las investigaciones, 7 de los 13 estudios analizan la efectividad de las redes sociales a la hora de usarlas como herramientas de promoción de la salud (53.8%); mientras que otros 2 analizan si las redes sociales son útiles o no para difundir información sanitaria en situaciones de emergencia (15.4%). El resto de los estudios analizan el uso de las redes sociales (1) para promover lo que se habla en una conferencia de salud (7.7%); (2) para reclutar casos de estudio para una investigación (7.7%); (3) como herramienta publicitaria (7.7%); y (4) para promover la alfabetización de la salud (7.7%).

Finalmente, cuanto al éxito o fracaso de estas iniciativas, podemos observar que los estudios de Bullen (2013), Naditz (2009), Pandey et al. (2010), Syred et al. (2014) y Trueland (2014) demuestran que el uso de las redes sociales ha tenido un impacto en las campañas o iniciativas que se han llevado a cabo (38.5%); mientras que el resto de los artículos incluidos en esta revisión concluyen a nivel general que las redes sociales han marcado una diferencia en las estrategias de comunicación de las instituciones, pero que hace falta trabajar más en los planteamientos para que su uso sea realmente efectivo (61.5%).

Discusión

En términos generales, aunque las instituciones usan las redes sociales como herramientas de promoción de la salud (así lo indican los estudios), mayoritariamente se están usando de manera poco efectiva. Según los registros analizados, generalmente (1) existe una falta de comunicación bidireccional entre las instituciones y los usuarios que acceden a los perfiles de las mismas; (2) el contenido que comparten en estas cuentas es escaso y poco interactivo (apenas hay imágenes o vídeos); y principalmente (3) están dirigidas en su mayoría por personal no cualificado.

La red social, por definición, es una herramienta de comunicación bidireccional. Como se ha podido observar en algunos de los estudios incluidos en esta revisión, en ocasiones las respuestas que proporcionan las organizaciones en redes sociales son más bien lentas (se tarda una media de entre 70 y 90 horas a contestar) o ni siquiera se llegan a producir (Fallon & Schmalzried, 2013). El propio estudio confirma que, en ocasiones, las instituciones usan las redes sociales más bien como un anexo a la página web habitual que como una herramienta de comunicación 2.0 con sus propias potencialidades, y por tanto, se desaprovecha su potencial comunicativo. Aunque las redes sociales son herramientas pensadas para fomentar el diálogo tanto entre los usuarios como entre los usuarios y los profesionales, estudios previos afirman que "históricamente, la comunicación unidireccional entre los ciudadanos y sus gobiernos ha predominado en Internet" (trad. a., Merwin Jr. et al., 2012: 85). Además, otro estudio afirma que los profesionales "utilizan las redes sociales con más frecuencia para la difusión unidireccional de mensajes que para comprometerse realmente con los públicos" (trad. a., Bortree & Seltzer, 2009; Rybal ko & Seltzer, 2010; citados en Lee & VanDyke, 2015: 535).

Por otro lado, si se quieren utilizar las redes sociales en el campo de la salud, se necesita más personal y que además esté entrenado para ello (Harris, Mueller, Snider & Haire-Joshu, 2013; Harris, Mueller & Snider, 2013b; Fallon & Schmalzried, 2013). Por ejemplo, algunos estudios afirman que las instituciones que tienen contratado un especialista en comunicación para llevar las redes sociales, registran un número de seguidores mayor (Harris et al., 2013b; Park, Rodgers & Stemmle, 2011; Thackeray et al., 2012). Asimismo, según Thackeray et al. (2012) las instituciones deben establecer un "plan de comunicación estratégica" (trad. a.) para usar las redes sociales de manera eficaz. No obstante, para poder mejorar la estrategia comunicativa de la institución, antes es necesario disponer de más datos acerca de la eficacia de las redes sociales en la comunicación en salud. Tener antecedentes permitiría a las propias organizaciones desarrollar directivas o consejos que invitarían a los profesionales a hacer un uso más responsable de estas herramientas, como proporcionar mejor contenido, ofrecer mejor información y más verificada, o dar más visibilidad a la institución que está detrás del perfil en cuestión; siempre dentro de las directrices marcadas por la estrategia de comunicación. Así lo afirma George (2011) en su estudio al decir que "una mejor educación, directrices, y políticas institucionales serían necesarias antes que los profesionales de la salud se sientan cómodos sumergiéndose plenamente en las plataformas de redes sociales como Facebook" (trad. a., George, 2011: 218).

En relación al contenido, Park et al. (2011) afirman que está bien que los usuarios generen su propio contenido, debatan entre ellos y lo compartan con otras personas, pero esta situación puede conllevar a que la calidad de la información sea pobre. No a cada paciente le afecta la enfermedad de la misma manera, y por tanto, la realidad que comparte es única y desde un solo enfoque. Estudios anteriores manifiestan que "la calidad del contenido generado por los usuarios varia drásticamente de excelente a abusivo o spam" (trad. a., Agichtein et al., 2008: 183), así que es necesario buscar el equilibro entre los mensajes generados por los usuarios (*user-generated content*) y los mensajes generados por los profesionales, sean o no especialistas en comunicación (*profesionally-generated content*). Como afirman Harris et al. (2013), "los departamentos de salud tienen una oportunidad única de usar las redes sociales para ofrecer este servicio esencial" (trad. a., Harris et al., 2013: 6), esto es, ofrecer a los usuarios contenido de calidad. Asimismo, estudios previos declaran que los factores clave que utilizan los consumidores para identificar fuentes fiables de información en la web 2.0 son "los conocimientos del comunicador, su experiencia, la imparcialidad de la fuente, la afinidad que tienen con la misma, y la confianza de la fuente dentro de la propia red social del consumidor" (trad. a., Borgatti & Cross, 2003, Health et al., 2007; citados en Welbourne & Grant, 2015: 10); de manera que, si se trabaja dentro de una estrategia, las instituciones parten de una posición de ventaja para convertirse en una fuente íntegra para los usuarios. Si además Harris et al. (2013) afirman que las personas que tienen problemas de salud consultan información sobre su condición principalmente a través de las redes sociales, las organizaciones deben usar estas herramientas para educar a los pacientes y evitar que accedan a fuentes de información no verificada o de procedencia dudosa, de tal manera que impidan poner en riesgo su salud.

Otra idea clave que se puede extraer de los estudios es que las redes sociales permiten a las organizaciones ser interactivas, aunque a juzgar por los resultados encontrados, la mayoría de ellas no están aprovechando esta ventaja. Park et al. (2011) afirman que la interactividad permite comprender mejor la información sanitaria, y además de conectar las redes sociales entre sí, permite a los usuarios de las mismas encontrar la información que están consultando en varios formatos. En un estudio anterior Kamel Boulos y Wheeler (2007) ya decían que "las tecnologías sociables de la web 2.0 tienen el potencial de promover el aprendizaje activo y comprometido, donde los participantes construyen su conocimiento a través de la interacción y la exploración social" (trad. a., Kamel Boulos & Wheeler, 2007: 18). Es necesario pues pasar del texto al vídeo, de la foto a la historia digital; de tal manera que la información se exprese en un lenguaje novedoso y atractivo para que conecte con el usuario que la consulta. Sin embargo, según Thackeray et al. (2012), las instituciones "no están capitalizando el potencial interactivo de las redes sociales" (trad. a., Thackeray et al., 2012: 5), ya que estas organizaciones aún tienen muy interiorizada la política del *one-way communication*. El mismo estudio apunta que quizá una de las causas es que existe un desajuste entre el contenido que publican estas organizaciones y el contenido que las audiencias prefieren (Thackeray et al., 2012). Cada vez son más los usuarios de redes sociales que buscan instituciones y compañías que se impliquen en este tipo de herramientas, y que se comuniquen con el usuario-consumidor a través de estos canales (Park et al., 2013). Como indica la literatura previa, "tener más posibilidades de interactuar ofrece al usuario la libre elección de escoger el contenido que quieren" (Oblak, 2005: 98), democratizando el conocimiento y la educación para la salud. En definitiva, si bien es necesario un cambio, precisamente son las instituciones las que utilizan un espectro más amplio de interactividad en cuanto a contenido se refiere (Park et al., 2011).

En cuanto a limitaciones de este artículo, la principal es que no se han encontrado estudios que se hayan desarrollado en España o en países de habla hispana. Este hecho limita el estudio a la hora de querer realizar comparaciones entre el uso del entorno 2.0 en el campo de la salud en el mundo anglosajón y el mundo de habla hispana. Por otro lado, la mayoría de las iniciativas se sitúan en Estados Unidos, cosa que puede proporcionar una visión ligeramente sesgada de las estrategias de uso de las redes sociales por parte de las instituciones a la hora de informar y promocionar la salud. Asimismo, la mayoría de los estudios están relacionados en analizar la eficacia del uso de las redes sociales por parte de las instituciones públicas para realizar promoción de la salud. Solamente 2 de los 13 estudios (15.4%) analizan el uso de estas herramientas en situaciones de emergencia. En términos comunicativos de coordinación interna entre las instituciones, la integración de las redes sociales supondría todo un reto de innovación, así que una futura línea de investigación podría comprobar más en profundidad la eficacia de las redes sociales en este tipo de situaciones de naturaleza crítica.

Por otro lado, en el estudio de Thackeray et al. (2012) aparece una idea interesante sobre la relación entre las redes sociales y los cambios de comportamiento, así que otra posible futura línea de investigación podría consistir en comprobar la eficacia e influencia que tienen estas herramientas en los cambios de hábitos de los usuarios que utilizan y consultan las redes sociales de las instituciones públicas, para ver si realmente influye en su comportamiento. En definitiva, las formas en que las instituciones de salud pública incorporan las redes sociales en sus quehaceres configurarán un espacio de reflexión y transformación social que, como define Díaz (2014), nos hará plantear la comunicación en salud “en un sentido estratégico y relacional” (Díaz, 2014: 8). Más allá de los usos instrumentales, estas herramientas propondrán cuestiones mucho más sustantivas sobre cómo pensar la comunicación organizacional sobre salud en su conjunto, de tal manera que se apueste por la misma “como una dimensión constitutiva y estratégica de las organizaciones” (Díaz, 2014: 12).

Conclusiones

Aunque las redes sociales están en crecimiento y empiezan a formar parte de las estrategias de comunicación de las instituciones públicas, “existe una escasez de datos científicos sobre la adopción de redes sociales en los entornos de salud pública” (trad. a., Thackeray et al., 2012: 1). No obstante, aunque son necesarios más estudios que analicen la eficacia del uso de estas herramientas por parte de las instituciones para difundir información sanitaria, las redes sociales son un buen instrumento para divulgar la información de una manera rentable pese a que falten recursos y personal que esté dispuesto a llevarlas (Park et al., 2011).

Bibliografía

Agichtein, E.; Castillo, C.; Donato, D.; Gionis, A. & Mishne, G. (2008). Finding High-Quality Content in Social Media. Proceedings of the 2008 International Conference on Web Search and Data Mining, 183-194.

Anderson, G.; Gleeson, S.; Rissel, C.; Wen, L. M. & Bedford, K. (2014). Twitter tweets and twaddle: twittering at AHPA National Health Promotion Conference. Health Promotion Journal of Australia, 25 (2), 143-146.

Bullen, P. B. (2013). Using a Mobile Photo Booth and Facebook to Promote Positive Health Messages Among Men Who Have Sex With Men in Cambodia. American Journal of Public Health, 103 (2), 251-252.

Centers for Disease Control and Prevention (2015). The Health Communicator's Social Media Toolkit [Guidelines]. Consultado el día 25 de junio de 2015 de la World Wide Web: http://www.cdc.gov/socialmedia/tools/guidelines/

Chopra, V. & McMahon Jr. L. (2011). HITECH, Electronic Health Records and Facebook: a health information trifecta. The American Journal of Medicine, 124 (6), 477-479.

Díaz, H. A. (2014). La Comunicación en la Educación para la Salud. Revista Española de Comunicación en Salud, 5 (1), 8-13.

Duggan, M.; Ellison, N. B.; Lampe, C.; Lenhart, A. & Madden, M. (2015). Social Media Update 2014. [Report]. Consultado el día 20 de junio de 2015 de la World Wide Web: http://www.pewinternet.org/2015/01/09/social-media-update-2014/

Eysenbach, G. (2011). Infodemiology and infoveillance: Tracking Online Health Information and Cyberbehavior for Public Health. American Journal of Preventive Medicine, 40 (5, S2), S154-S158.

Fallon, L. F. & Schmalzried, H. D. (2013). A Study on the Responsiveness of Local Health Departments that Use Facebook. Homeland Security & Emergency Management, 10 (1), 1-8.

George, D. R. (2011). Friending Facebook? A Minicourse on the Use of Social Media by Health Professionals. Journal of Continuing Education in the Health Professions, 31 (3), 215-219.

Govette, J. (2014). 24 Outstanding Healthcare Social Media Statistics. [Pulse]. Consultado el día 25 de junio de 2015 de la World Wide Web: https://www.linkedin.com/pulse/20140428161148-39605227-24-outstanding-statistics-figures-on-how-social-media-has-impacted-the-health-care-industry

Harris, J.; Mueller, N.; Snider, D. & Haire-Joshu, D. (2013). Local Health Department Use of Twitter to Disseminate Diabetes Information, United States. Preventing Chronic Disease, 10, E70.

Harris, J.; Mueller, N. & Snider, D. (2013b). Social Media Adoption in Local Health Departments Nationwide. American Journal of Public Health, 103 (9), 1700-1707.

Hawn, C. (2009). Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. Health Affairs, 28 (2), 361-368.

HIMSS Privacy & Security Committee (2013). Social Media in Healthcare: Privacy & Security Considerations (White Paper). [Resource Library]. Consultado el día 30 de junio de 2015 de la World Wide Web: http://www.himss.org/ResourceLibrary/GenResourceReg.aspx?ItemNumber=17244

Hunter, P.; Oyervides, O.; Grande, K.; Prater, D.; Vann, V.; Reitl, I. & Biedrzycki, P. (2014). Facebook-Augmented Partner Notification in a Cluster of Syphilis Cases in Milwaukee. Public Health Reports, 129 (S1), 43-49.

Kamel Boulos, M. N. & Wheeler, S. (2007). The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education. Health Information and Libraries Journal, 24, 2-23.

Lee, N. M.; VanDyke, M. S. (2015). Set It and Forget It: The One-Way Use of Social Media by Government Agencies Communicating Science. Science Communication, 37 (4), 533-541.

Merwin Jr., G. A.; McDonald, J. S.; Merwin, K. A.; McDonald, M. & Bennett Jr., John R. (2012). “Local Governments and Social Networking: Do You Speak Our Language?” en E. Downey & M. Jones (eds.), *Public Service, Governance and Web 2.0 Technologies. Future Trends in Social Media* (pp. 84-98). Hershey PA: IGI Global.

Naditz, A. (2009). Military health services target youth through social networking tools like Twitter, YouTube. Telemedicine Journal and e-Health, 15 (7), 623.

Oblak, T. (2005). The Lack of Interactivity and Hypertextuality in Online Media. International Communication Gazette, 67 (1), 87-106.

Pandey, A.; Patni, N.; Singh, M.; Sood, A. & Singh G. (2010). YouTube As a Source of Information on the H1N1 Influenza Pandemic. American Journal of Preventive Medicine, 38 (3), e1-e3.

Park, H.; Rodgers, S. & Stemmle, J. (2011). Health Organizations’ use of Facebook for health advertising and promotion. Journal of Interactive Advertising, 12 (1), 62-77.

Park, H.; Rodgers, S. & Stemmle, J. (2013). Analyzing Health Organizations’ Use of Twitter for Promoting Health Literacy. Journal of Health Communication: International Perspectives, 18 (4), 410-425.

Pew Research Center (2012). Health Fact Sheet. [Fact Sheets]. Consultado el día 20 de junio de 2015 de la World Wide Web: http://www.pewinternet.org/fact-sheets/health-fact-sheet/

Phillips, S. (2007). A brief history of Facebook. [Technology]. Consultado el día 30 de junio de 2015 de la World Wide Web: http://www.theguardian.com/technology/2007/jul/25/media.newmedia

Scanfeld, D.; Scanfeld, V. & Larson, E. L. (2010). Dissemination of health information through social networks: Twitter and antibiotics. American Journal of Infection Control, 38 (3), 182-188.

Social Media. (2015). En Merriam-Webster Dictionary [Online]. Disponible: Encyclopædia Britannica Company [sin fecha].

Syred, J.; Naidoo, C.; Woodhall, S. & Baraitser, P. (2014). Would You Tell Everyone This? Facebook Conversations as Health Promotion Interventions. Journal of Medical Internet Research, 16 (4), e108.

Thackeray, R.; Neiger, B.; Smith, A. & Van Wagenen, S. (2012). Adoption and use of social media among public health departments. BMC Public Health, 12, 242.

Trueland, J. (2014). Make the pledge. Nursing Standard, 28 (26), 20-23.

Urrútia, G. & Bonfill, X. (2010). Declaración PRISMA: una propuesta para mejorar la publicación de revisiones sistemáticas y metaanálisis. Medicina Clínica, 135 (11), 507-511.

Welbourne, D. J. & Grant, W. J. (2015). Science communication on YouTube: Factors that affect channel and video popularity. Public Understanding of Science, 0963662515572068, 1-14.

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4.3 Study II

Institutional pain communication via Twitter by Spanish and US pain societies: analysis of levels of use and engagement

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Institutional pain communication via Twitter by Spanish and US pain societies: Analysis of levels of use and engagement

ABSTRACT

Pain is a complex issue, and often patients feel isolated. Social media are arising as instruments where users find support and spaces to express their pain. This study analyses how two pain institutions – the Spanish Pain Society (SED) and the American Pain Society (APS) – are creating messages and communicating them through Twitter, by examining their profile content and procedures. A comparative analysis was applied to 2474 tweets corresponding to the period running from the inception of the profiles (APS July 2010, SED March 2013) to February 2016. Both profiles manage aspects like targeted audiences and referential content quite well, whereas frequency and engagement with users would need to be improved. Although the two institutions are already using this social media tool, we suggest that both organizations would benefit from developing a social media strategy. Nevertheless, further research is needed in order to understand deeply how pain is communicated via Twitter.

KEYWORDS

pain
institutional communication
Twitter
health
social media
organizations

INTRODUCTION

Health and social media

Twitter, Facebook and similar social media platforms have been with us for more than a decade (van Dijck 2013) and have become constructive tools with an impact on how people acquire information (Scanfeld et al. 2010; Kind and Evans 2015). In a digitized world most people seek information on the Internet, including on health-related topics (Cline and Haynes 2001). Even so, 'the question of health communication on the Internet is increasingly complicated. E-health technologies, personalized e-health systems and multiple forms of social media are changing health communication at every level' (Torkkola 2016: 22).

Recent studies (Scanfeld et al. 2010; Robillard et al. 2013) indicate that patients recognize that their online medical consultations have an impact on decision making about health, standardizing the *participatory healthcare* concept (Sosnowy 2014). Through social media, for instance, health care organizations can inform, educate and empower users and can also collect data to analyse health trends, among other uses (Thackeray et al. 2012; Lafferty and Manca 2015). Interestingly, 'Internet users who seek health information are more attracted to social networking sites than to blogs and online support groups' (Park et al. 2013: 412; Mehta and Atreja 2015). In this sense, Moorhead et al. suggests that 'social media allows users to generate peer-to-peer discussion in a way not enabled by traditional websites' (2013: e85).[1]

At the same time, social media are also changing the patient-provider relationship (Chretien and Kind 2013), now no longer reflecting superiority but equity. Via social media, health professionals join virtual communities where they 'read news articles, listen to experts, research new medical developments, network, and communicate with colleagues regarding patient issues' (Modahl et al. 2011, cited by Househ 2013: 246). Patients, meanwhile, can take control of their health by seeking information about their illnesses (Scanfeld et al. 2010; Buchanan and Beckett 2014), for subsequent discussion with their health care provider (Merolli et al. 2013; Sosnowy 2014; Chretien and Tuck 2015). Besides, 'social media can be used to provide a valuable and useful source of peer, social, and emotional support to individuals, including those with various conditions/illnesses' (Moorhead et al. 2013: e85). However, all that glitters is not gold, at least for institutions. In this new environment of patients actively seeking information and sharing their experiences, sensitive health information is exposed to all kinds of audiences without any control.

A double-edged sword

The use of social media in health care raises certain concerns for institutions regarding privacy and misinformation. The patient-physician relationship is no longer two-way, because social media 'provide important spaces for people with illnesses to build community, engage in activism, and enact resistance' (Sosnowy 2014: 316; De la Torre-Díez et al. 2012; Mehta and Atreja 2015). In social media, many different individuals participate in medical consultations: the patient, their physician, their family, other patients, other providers – not to mention many anonymous people with something to say. The concept of privacy is blurred because information shared on social media is no longer in the control of the patient, and they cannot know who may be reading it (Hawn 2009). As DeCamp points out, nowadays 'more individuals choose to

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[1] A 2005 study stated that 'rapid diffusion of Internet technology within the public sphere has placed an unprecedented amount of health information within reach of general consumers' (Hesse et al. 2005: 2618); an affirmation that is still valid today. Traditional health information searches were mostly an individual task (Cline and Haynes 2001). Now, social media offers patients 'collaboration between users and a social interaction mechanism for a range of individuals' (Moorhead et al. 2013: e85), giving them an instant feedback (Park et al. 2011). Also, these tools 'let users share information that is consumer-centric and consumer controlled, enabling anonymity or personal connection' (Korda and Itani 2013: 16).

share what was previously considered sensitive' (2015: 121). Nevertheless, ensuring privacy in these platforms, designed to be open and friendly, is quite difficult (Mehta and Atreja 2015); because 'patients using the web for health information face challenges of variability in the quality of content, privacy issues and consumer fraud' (Mehta and Atreja 2015: 122).

Health care providers face issues of potential misinformation of patients on a regular basis (Ahmad et al. 2006). As Kilaru et al. points out, 'with thousands upon thousands of health-related web pages, the sheer volume of online content dilutes attention to any single health message' (2014: 1633–34). Misinformation is a complex issue for institutions, because 'public health challenges stemming from online misinformation are at the complex intersection of scientific research, mass media, and the emergence of social network activism through user-created content and consumer reception of information' (Seymour et al. 2015: 517). In other words, multiple health information sources are available, but not all of them are reliable. It seems, however, that patients, and especially those with chronic pain, overlook this issue, as they continue to share personal stories online, looking for the support that they may not receive in their social setting (Merolli et al. 2013). In this context, health-related institutions need to be present in social media in order to point users and patients towards, and show them how to use, reliable sources of information.

The institutional dilemma of social media use

In a world where conversations 'about public health topics are happening whether we participate or not' (Heldman et al. 2013: 12), it is important for health care organizations and other health-related institutions to embrace the use of social media. Users, and above all, patients, increasingly seek organizations that participate in and communicate through these channels (Park et al. 2013). In this sense, Lardi and Ledergerber affirm that 'interacting with followers on social networks is a crucial part to building a strong presence' (Lardi and Ledergerber 2013: 86). Organizations should clearly be involved in social media (Weiner 2015), but not at any price. A major risk is loss of authority:

> All these new contributions to health communication show that the one-way process of mass communication, where the source of health information was mainly the health institutions and professionals, and where lay people were mostly in the role of passive target groups, is losing its hegemonic position.
>
> (Torkkola 2013: para. 1)

This transition has occurred in all kind of health care organizations, because they began to participate in the social media world later than patients (Thackeray et al. 2012). Harris et al. suggests that this happens because institutions face 'organizational barriers common to governmental public health care organizations' (2013a: 1706). The obstacles include 'lengthy approval processes for new projects, policies that hinder social media use once it is adopted, a lack of a reliable and fast Internet connection and firewalls that prohibit social media use by employees' (Harris et al. 2013a: 1706). In the absence of official sources, patients began to seek information elsewhere, often finding it in the form of non-official user-generated content.[2] As a consequence, institutions started to lose influence as a source of information for their patients.

[2] For Park et al. (2011), users may of course create their own content, but it is generally low-quality information. It is the responsibility of institutions and other health-related organizations to create more professionally generated content in order to reinstate themselves as points of reference or as a source of credibility.

To reinstate their status, health care organizations need to improve the productive performance of their social media profiles. Basically, institutions need to define an online communication strategy designed to achieve several key goals and covering appropriate content for the user, proper communication of that content, the creation of content aimed at promoting health and, above all, more and better interaction with users, with the ultimate aim of creating shared meaning in which dialogue could be promoted. As Lardi points out, 'a lack of content planning, resources and clear responsibilities mean that the channels [like a Twitter profile] sometimes fall dormant and eventually lose the interest of costumers' (Lardi 2013: 18). Neiger et al. suggest the following in their study:

> Before attempting to create a social media presence that transcends one-way messaging and actually engages audiences, health promotion practitioners should consider four key strategic issues: (a) decide what the organization is trying to accomplish with social media (e.g., goals and objectives), (b) identify specific audiences of interest to the organization and its programs and tailor strategies to invite them into the social media conversation, (c) identify benefits the organization can offer audience members within the context of predetermined goals and objectives, and (d) identify what the organization wants audiences to do (e.g., create or promote content, respond to messages, share experiences, participate with the organization off-line).
>
> (2013: 158)

Therefore, it is evident that building a presence in social media is not an easy task. There are many different tools, and each one has its own specificities. In our study we focus specifically on Twitter. Among all the possibilities, this instrument 'has emerged as one of the most popular microblogging platforms that allows users to send and read short text-based messages limited to 140 characters' (Robillard et al. 2013: 2). Also, regarding to health organizations, the use of Twitter 'may be an effective way to reach their citizens and promote healthier life styles, adherence to treatment, or improve knowledge about any disease' (Carrillo-Larco 2012: 755).

As suggested earlier, patients are used to seek health information through social media: among all of the options, Twitter stands out as an instrument for searching health-related information (Scanfeld et al. 2010; Robillard et al. 2013). Also, as with any other social media platform, it is important to keep profiles up to date in order to maintain the interest (Lardi 2013; Dawley 2015). Nevertheless, although there are many guidelines about general social media use in health care, few organizations use them in a proper and coherent way (Heldman et al. 2013).

Challenges in communicating pain through social media

Pain patients are one of the groups with most social media presence (Gonzalez-Polledo 2016). Before we go on to explore how pain is communicated through social media, we should point out that there are two significantly different kinds of pain: acute pain and chronic pain. According to the US Federation of State Medical Boards, 'acute pain is the normal, predictable physiological response to a noxious chemical, thermal or mechanical stimulus and typically is associated with invasive procedures, trauma and disease [and] generally is time-limited, lasting six weeks or less', whereas 'chronic pain is a state in which pain persists beyond the usual course of an acute disease or healing of an injury (e.g., more than three months)' (2013: 17).

Although acute and chronic pain are mainly distinguished in terms of duration, this is not the only difference. In terms of expression, pain can be manifested verbally (through questionnaires like PCQ[3] or with vocalized expressions like 'my arm hurts') or at a non-verbal level (through photographs, facial expressions, movements, etc. [Mesko et al. 2011; Walsh et al. 2014]). Note that even though 'the nature of pain makes objective measurement impossible' (Breivik 2008: 17), it is still essential to have assessment tools (Mann and Carr 2009). Here lies the problem: although acute pain 'can be reliably assessed' (Breivik 2008: 17), chronic pain assessment 'require multidimensional qualitative tools and health-related quality of life instruments' (Breivik 2008: 17). So, in the case of chronic pain, subjectivity plays an important role (NIH Medline Plus 2011).

To illustrate, certain illnesses (like fibromyalgia) are difficult to diagnose because it is difficult to obtain clinical evidence – and because symptoms can come and go over time (Mayo Clinic Staff 2014). In these cases, patients struggle 'to be taken at their word – to have doctors, friends, and family believe that they're reliable narrators of their own experiences' (Leigh 2015). In these situations, patients are trying to communicate their pain – and this is where new technologies are assuming a central role. It has been shown that social media use has a positive impact on the management of certain illnesses, and one area of positive impact is chronic pain (Merolli et al. 2013). Patients with chronic pain have found new ways to express how they feel about their pain – and they have transformed narratives (Gonzalez-Polledo and Tarr 2014). Therefore, social media act as a loudspeaker for pain patients, enabling more widespread distribution of pain-related messages and 'potentially challenging excommunication' (Gonzalez-Polledo and Tarr 2014: 14). For some experts, these tools act as an amplifier, and are 'becoming health devices where the experience of living with pain is normalized and made newly visible' (Gonzalez-Polledo 2016: 2).

Moreover, in chronic pain management, the use of social media also has a function of attenuation. In some cases, using these tools has meant an improvement of psychological well-being of patients in terms of handling stress, anxiety, etc. (Merolli et al. 2013). Online support groups are fundamental for pain patients (Mehta and Atreja 2015), since pain – and above all its chronic form – is mostly an invisible and sometimes stigmatized illness (Jackson 2005). For this reason, these communities are very popular among patients with chronic conditions (Mehta and Atreja 2015). In this kind of 'online neighbourhood', chronic pain sufferers find the support that is often lacking in their ordinary lives, and alleviate pain thanks to communication. Consequently, pain institutions and organizations need to take social media into account, both as an experimental assessment tool for the sharing of experiences and as a new way to educate both patients and families about their illnesses.

STUDY AIM

As several studies have suggested that online communities are fundamental for patients (Merolli et al. 2013; Moorhead et al. 2013; Mehta and Atreja 2015) – especially those with pain or chronic conditions – our study aim was to find

[3] Pain-Coping Questionnaire (Huguet et al. 2009).

out how these two pain institutions – the Spanish Pain Society (SED) and the American Pain Society (APS) – are creating messages and communicating them via Twitter, in order to analyse if both institutions are engaging with its audience.[4]

Our approach was based on examining the content shared in their respective Twitter profiles, @Sedolor and @AmericanPainSoc. More specifically, we analysed six key aspects: (1) type of content; (2) interactivity of the profiles; (3) use of hashtags; (4) targets of the messages; (5) frequency; and (6) presence of pain-related tweets. In this research, content analysis was tested as a potentially useful tool for exploiting the specificities of how Twitter operates.

METHODS

Social media analysis is a complex issue, and the studies described in the literature have tended to evaluate the data in different ways. For this reason, our objective was to create an exploratory methodology for analysing specific Twitter profiles, in our case, associated with pain organizations. To implement our matrix analysis, we consulted studies on tourist destination brands, museums and online communication and Twitter content classification; and also examined studies of health communication in social media. From this literature review (Dann 2010; Thackeray et al. 2012; Park et al. 2013; Huertas and Mariné 2014; Cordón Benito and González González 2016), we created an analysis table that included the above-mentioned six categories (content, interactivity, hashtags, targets, frequency and pain-related tweets).

Due to the specificities of the analysed profiles, we considered that the most important category of our analysis table is interactivity, bearing in mind Park et al., who, drawing on various authors stated that, in health communication, 'interactivity enables social networking sites to facilitate consumers' understanding of health information, increases word of mouth among interpersonal networks, and improves consumers' self-management behaviors' (Nutbeam 2000; Kalichman et al. 2002; Guendelman et al. 2002, cited by Park et al. 2011: 63). Also, regarding pain, another study has suggested that 'by empowering the patient with health care options, belief in the pain experience is communicated in a way that could counter experiences of learned helplessness' (Newton et al. 2013: 168).

Data collection

For this study, 2474 tweets were analysed (1727 tweets from the SED account [@Sedolor] and 747 tweets from the APS account [@AmericanPainSoc][5]) published over the period running from the inception of the two profiles (March 2013 and July 2010, respectively) to February 2016.

In March 2016, we captured all the tweets from both profiles using the Omnicity freeware (http://omnicity.com/ot/), which allows 3200 tweets to be recovered from a specific profile.[6] The tweets were manually compiled in a table with a date and a URL link for each tweet.

Coding

The final sample was manually coded using an exploratory social media analysis methodology developed by our research group for previous research. This methodology was tested in our comparative analysis of pain organization profiles.

[4] In this case, mainly pain patients looking for information or support. About its stance regarding the social media (what Neiger et al. (2013: 58) states to be the social media 'goals and objectives' of the institution), we have only implicit references on the SED website: it aims 'to use new media and social networks as a tool to make it easier (for both members and patients) to communicate with the SED' (Neira 2013).

[5] The APS had 7345 followers whereas the SED had 3284 followers (as of 10 August 2016).

[6] We used Omnicity because neither the SED nor the APS exceeded the number of tweets that the tool can capture.

Each tweet was analysed individually and coded in an analysis table reflecting six main categories and fourteen subcategories, as follows: content (topics, typologies, images, videos, links); interactivity (user interactions, retweets, likes); hashtags (average number of hashtags, hashtags used); targets (external, internal); frequency; and pain-related tweets (pain-related, non-pain-related).[7]

For the content category, we analysed the most recurrent topics in each profile, and drawing on Dann's (2010) classification of Twitter content, we created four subcategories: institutional tweets, news-related tweets, educational tweets and science community tweets.[8] As for typologies, we drew on Cordón Benito and González González's (2016) classification,[9] but included an additional level: profile tweets, retweets, answers and quote tweets. In the case of retweets, we checked which profiles the SED and the APS were endorsing and created five subcategories, based on Park et al. (2013): health professionals; institutions and associations; media and journalists; educational; and others. Finally, we added three subcategories (images, videos, links) regarding the narrative elements of a tweet, following Huertas and Mariné (2014) and Cordón Benito and González González (2016) studies. As Gausepohl (2016) states, 'sharing links […] is a great way to make your Twitter feed more engaging'; and we suggest that the same applies to images and videos.

For the interactivity category, drawing on the social media analysis conducted by Huertas and Mariné (2014) for destination tourist brands, we created three subcategories: user interactions, retweets and likes. Of these subcategories, Huertas and Mariné (2014) consider only user interactions as an interactivity measure. Although retweets and likes are related to the visibility of the social media profile (Huertas and Mariné 2014), they are included in interactivity because, on clicking the corresponding buttons, the user is also interacting with the profile (Thackeray et al. 2012).

For the hashtags category, following Cordón Benito and González González's (2016) study, we created two subcategories: average number of hashtags and hashtags used. Regarding the targets category, two subcategories (Huertas and Mariné 2014) were created: external targets (all kind of audiences) and internal targets (professional groups, like health care providers or nurses).

Also, we added a category for the frequency parameter, following Huertas and Mariné (2014) study. Finally, as this research refers to pain organizations, we considered it appropriate to add a pain-related tweets category, in order to determine how many tweets in each profile were about pain. This category was thus broken down into two subcategories: pain-related tweets and non-pain-related tweets.

The data analysis was performed for all tweets coded according to the above categories and subcategories.

RESULTS

Content

Figure 1 shows the results for content, specifically, tweet typologies, classified in four categories: profile tweets (posted by the person in charge of the profile), retweets (posted by other users), quote tweets (tweets that mention other tweets), and answers (tweets that start with the @statement). Both profiles showed similar results concerning retweets (18.1%, *n*=125 for the APS; and 17.5%, *n*=303 for the SED). For quote tweets and answers, percentages

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[7] According to the study aim, we coded our data in these five main categories (content, interactivity, hashtags, frequency, targets) in order to find out how the SED and the APS are creating and communicating messages through Twitter. A sixth category (pain-related tweets) was added to see if the content posted by the profiles is related to pain or not.

[8] In Dann's (2010) study, the categories were 'phatic' (institutional tweets), 'news' (news-related tweets) and 'pass along' (educational tweets). We added the science-community tweets category to reflect the specificities of our research.

[9] Cordón Benito and González González's (2016) classification refers to 'tweet', 'answer' and 'retweet'.

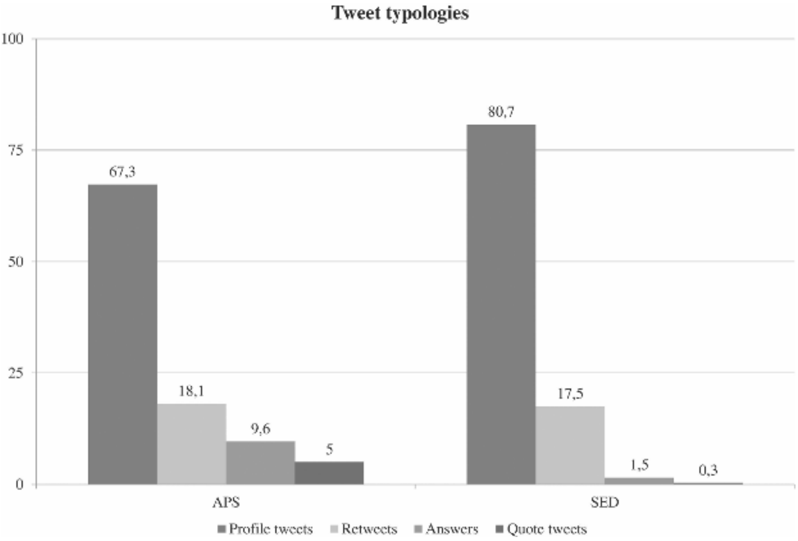


Figure 1: Content (tweet typologies).

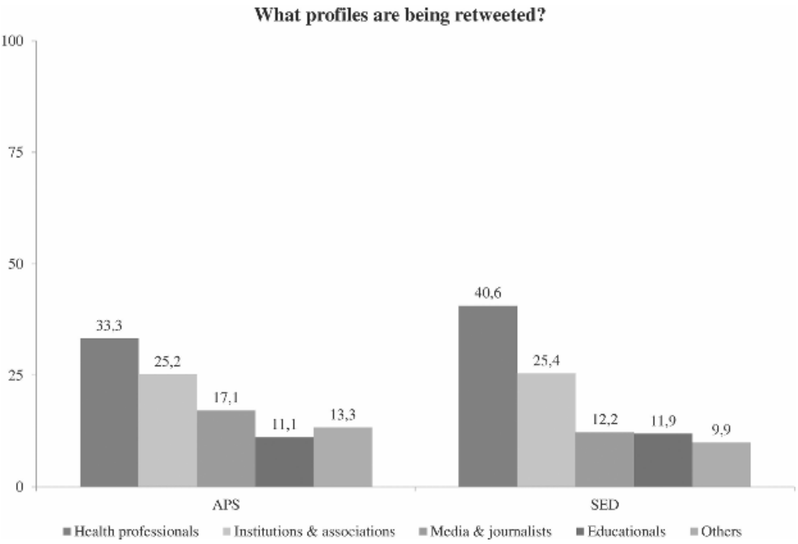
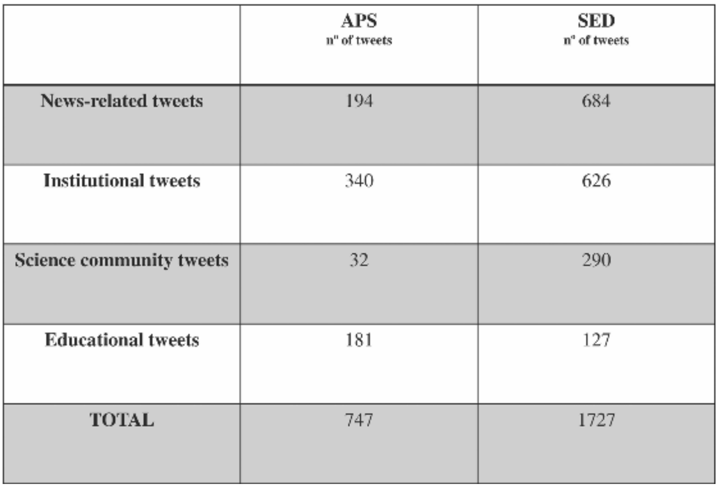


Figure 2: Retweeted profiles.

were higher for the APS: 5% (*n*=37) and 9.6% (*n*=72), respectively, versus 0.3% (*n*=5) and 1.5% (*n*=25) for the SED. As for profile tweets, the SED posted more of its own content than the APS: 80.7% (*n*=1394) and 67.3% (*n*=503), respectively.

In the case of the retweets subcategory, we also looked at the profiles that the APS and the SED were endorsing. These tweets were classified in five subcategories: health professionals (physicians, nurses, etc); institutions and associations (pain or non-pain-related, but related to health); media and journalists; the educational sector (colleges or schools), and others (private sector



	APS n° of tweets	**SED** n° of tweets
News-related tweets	194	684
Institutional tweets	340	626
Science community tweets	32	290
Educational tweets	181	127
TOTAL	747	1727

Table 1: Content (topics).

profiles, etc). Figure 2 shows that the results were very similar for both the APS and the SED.

A high proportion of the SED retweets (40.6%, *n*=123) came from health professionals, followed by institutions and associations (25.4%, *n*=77); the remaining retweets were accounted for by media and journalists (*n*=37, 12.2%), the education sector (*n*=36, 11.9%) and others (*n*=30, 9.9%). As for the APS profile, around a third of retweets came from health professionals (*n*=45, 33.3%), again followed by institutions and associations (25.2%, *n*=34); with the remaining retweets accounted for by media and journalists (*n*=23, 17.1%), others (*n*=18, 13.3%) and the education sector (*n*=15, 11.1%). Both profiles tended to retweet posts by physicians, nurses and institutions; and most retweets were pain-related (as indicated by the biographical description of each Twitter profile).

Table 1 shows the most recurrent topics, classified in four categories: institutional tweets (schedule tweets [events], political statements, and tweets with statistical pain data); news-related tweets (from newspapers or magazines); educational tweets (tweets that talk about health situations or recommendations, but the advice given was in an external link outside the Twitter platform); and science community tweets (mostly peer-reviewed articles).

A high proportion of SED tweets (39.6%, *n*=684) were news-related tweets and over a third (36.2%, *n*=626) were institutional tweets; of the remaining tweets, 16.8% (*n*=290) were science community tweets and 7.4% (*n*=127) were educational tweets. Adding institutional and news-related tweets together, three quarters (75.8%, *n*=1310) of the tweets shared information from external sources, pointing to very low presence of educational content.

As for the APS, nearly half (45.5%, *n*=340) of its tweets were institutional tweets and around a quarter each were news-related tweets (26%, *n*=194) and educational tweets (24.2%, *n*=181); with science community tweets accounting for the remaining 4.3% (*n*=32). The institutional and news-related tweets added together accounted for just under three quarters of the tweets (71.5%, *n*=534), indicating that the problem of misinformation was not being addressed. Although educational content was slightly higher than for the SED, in both cases it represented only a minor share of total tweets (see Table 1).

	LINKS	IMAGES	VIDEOS
APS	0,6 links/tweet	0,0 images/tweet	0,0 videos/tweet
SED	0,8 links/tweet	0,1 images/tweet	0,0 videos/tweet

Table 2: Presence of images, videos and links.

Finally, the content parameter was also analysed in terms of images, videos and links included in the tweets. Table 2 shows similar results for the APS and the SED.

Both profiles have in common that they did not use images and videos as a narrative resource (few tweets included these elements). In both cases, there were tweets with links to external sources of audio-visual content, but the user had to exit the Twitter platform to access the content.[10]

The main difference between the SED and the APS profiles was in the use of links as tweet content, overall under 1 on average (Table 2). The SED average was 0.8 links per tweet compared to an APS average of 0.6 links per tweet, indicating that the SED made better use of links than the APS. On average, almost every SED tweet contained a link that served to expand the content of the tweet; however, some tweets might have had several links and some may have had none at all.

Interactivity

The interactivity parameter was analysed first in terms of user interactions. This subcategory reflects the average number of interactions with users via tweets. In this case, the averages for the APS and the SED were 0.2 user interactions and 0.1 user interactions per tweet, respectively, indicating that users interacted very little with the profiles in both cases. Nevertheless, we can analyse the numbers from other perspective.

As we stated earlier, the APS profile has 612 tweets of own content (adding up profile tweets, quote tweets and answers). A high proportion of these tweets (87.6%, *n*=536) did not receive any interaction; while the remaining tweets (12.4%, *n*=76) received one or more user interactions (see Table 3). Taking into account that the APS profile has 72 answer tweets (as Figure 1 shows), we can note that APS answered 50.3% of the interactions from users. As for the SED, the profile has 1424 tweets of own content. Again, a high proportion of these tweets (92.3%, *n*=1314) did not receive any interaction; while the remaining tweets (7.7%, *n*=110) received one or more user interactions (see Table 3). Considering that the SED profile has 25 answer tweets (as Figure 1 shows), we can say that the SED answered only 17.6% of the interactions from users.

We also looked at the average number of likes and retweets for both accounts (Table 4). The APS had an average of 1.5 retweets per tweet, whereas the average for the SED rose to 2.3 retweets per tweet (almost a point higher). The average number of likes per tweet was similar for both accounts (0.8 for SED versus 1.1 for APS). Although the APS account had more followers than the SED account (7345 versus 3284[11]), the SED generated more engagement

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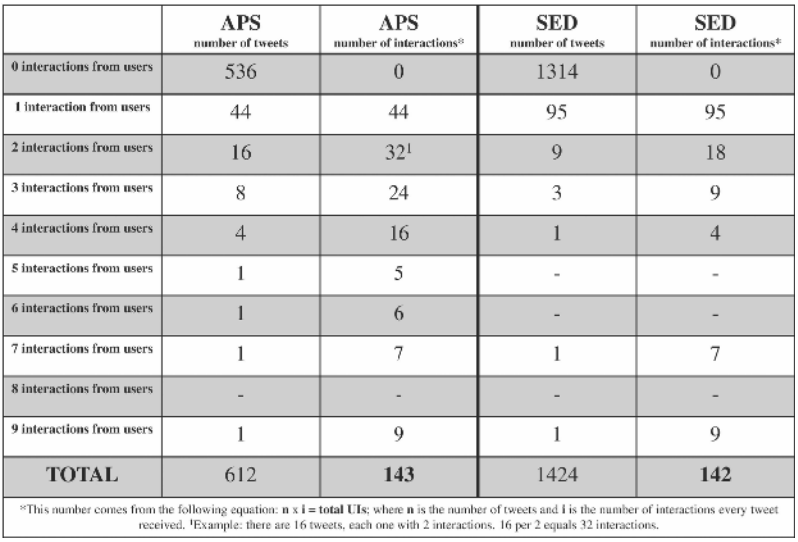
[10] A recent Facebook feature called 'instant articles' enables 'news publishers to distribute articles to Facebook's app that load and display as much as ten times faster than the standard mobile web' (Facebook 2017, para. 1). In other words, users can read the content of the links inside the Facebook interface, without leaving the app. Several news report that Twitter is also working on this feature (Lesemann 2016).

[11] Number of followers as of 10 August 2016.



	APS number of tweets	**APS** number of interactions*	**SED** number of tweets	**SED** number of interactions*
0 interactions from users	536	0	1314	0
1 interaction from users	44	44	95	95
2 interactions from users	16	32[1]	9	18
3 interactions from users	8	24	3	9
4 interactions from users	4	16	1	4
5 interactions from users	1	5	-	-
6 interactions from users	1	6	-	-
7 interactions from users	1	7	1	7
8 interactions from users	-	-	-	-
9 interactions from users	1	9	1	9
TOTAL	612	**143**	1424	**142**

*This number comes from the following equation: **n** x **i** = **total UIs**; where **n** is the number of tweets and **i** is the number of interactions every tweet received. [1]Example: there are 16 tweets, each one with 2 interactions. 16 per 2 equals 32 interactions.

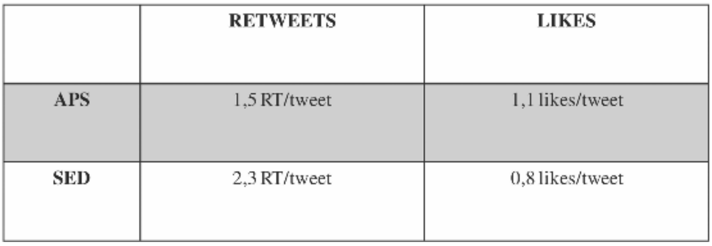
Table 3: Display of user interactions.

with its users. Note that, to calculate the averages, we only took profile tweets, quote tweets and answers into account.

Hashtags

Table 5 shows the results for the five most used hashtags, all pain-related except for the #ReadByQxMD hashtag (related to peer-reviewed articles). The five most used hashtags by the SED were #ReadByQxMD (*n*=241), #sedolor (*n*=92), #DíaMundialDolor (*n*=41), #dolor (*n*=28) and #dolorescorial (*n*=24). Three of the pain-related hashtags (#sedolor, #DíaMundialDolor, #dolor) were generic and the remaining hashtag (#dolorescorial) referred to a scientific conference on pain. The five most used hashtags by the APS were #ampainsoc (*n*=125), #pain (*n*=86), #APS15 (*n*=60), #pain101 (*n*=38) and #ASAPainUpdate (*n*=25). Two of the hashtags (#ampainsoc and #pain) were generic, another two (#pain101 and #ASAPainUpdate) were hashtags used to participate in a Twitter chat about pain and, finally, the #APS15 hashtag referred to a pain conference.

Table 6 shows the average number of hashtags for the two profiles, in both cases less than one (that is, under one hashtag per tweet). The hashtag



	RETWEETS	**LIKES**
APS	1,5 RT/tweet	1,1 likes/tweet
SED	2,3 RT/tweet	0,8 likes/tweet

Table 4: Retweets and likes.

	5 MOST USED HASHTAGS
APS	548 hashtags used, of which the most used are: #ampainsoc (125), #pain (86), #APS15 (60), #pain101 (38), #ASAPainUpdate (25)
SED	512 hashtags used, of which the most used are: #ReadByQxMD (241), #sedolor (92), #DíaMundialDolor (41), #dolor (28), #dolorescorial (24)

Table 5: Most used hashtags.

	HASHTAGS
APS	0,9 hashtags/tweet
SED	0,4 hashtags/tweet

Table 6: Average number of hashtags.

average for the APS was 0.9 hashtags per tweet; for the SED this average dropped significantly to 0.4 hashtags per tweet. The fact that almost every APS tweet contained a hashtag is significant, as hashtags serve 'to make the content you share on the platform visible to users beyond your own followers' (Gausepohl 2016: Twitter hashtags section, para. 2). Note, however, that the numbers are averages: some tweets may have had several hashtags and some tweets may not have had any hashtags. Even so, the data shows that the APS makes more use of hashtags than the SED.

Targets

Tweets were classified in two subcategories (see Table 7) according to targets: external tweets (addressed to all kind of audiences) and internal tweets (addressed to specific groups, whether members of an organization or nurses, clinicians, journalists, etc). The SED profile addressed most of its tweets to external targets (*n*=1347; 78%), with the remaining 22% (*n*=380) addressed to internal targets, whether health or communication professionals. Results for

	EXTERNAL TARGETS	**INTERNAL TARGETS**
APS	551 tweets	196 tweets
SED	1347 tweets	380 tweets

Table 7: Targets.

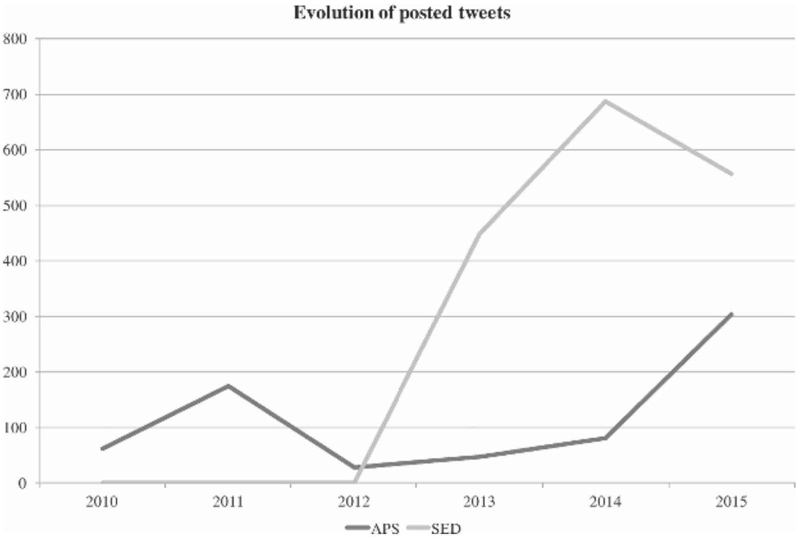


Figure 3: Evolution in tweet frequency.

the APS profile were similar, but the number of tweets addressed to internal targets rises to 26.2% (*n*=196). The APS therefore makes a more closed use of its account than the SED (which addresses a quarter of its tweets to internal targets).

Frequency

Figure 3 shows the evolution of tweets posted by the two profiles (from inception to December 2015). Although its Twitter profile only appeared in 2013, SED uses Twitter more frequently than the APS. The @AmericanPainSoc account has tended to maintain a low frequency of posts (*n*=61 in 2010, *n*=174 in 2011, *n*=28 in 2012, *n*=47 in 2013 and *n*=81 in 2014), although its level of activity did increase significantly in 2015 to *n*=303; whereas the @Sedolor profile has been quite constant in terms of post frequency in its years of existence (*n*=448 in 2013, *n*=687 in 2014 and *n*=557 in 2015). Figure 3 shows how the APS does not seem to have embraced the use of social media tools in their communication strategy: in four separate years, its posts numbered under 100 (if the profiles were being used regularly, this number of tweets would be posted in less than two months[12]).

Pain-related tweets

Finally, the last category included in our analysis was the pain-related tweets parameter. Of the 2474 SED and APS tweets analysed, 80% (*n*=1981) were pain-related tweets, leaving 19.9% (*n*=493) tweets as non-pain-related communications.

Broken down, the results were slightly different for the two organizations. For the APS, 68.7% (*n*=513) of the tweets were pain-related, wherever 31.3% (*n*=234) were non-pain-related tweets. The SED posted relatively more pain-related tweets that the APS: 85% (*n*=1468) pain-related tweets versus 15% (*n*=259) non-pain-related tweets.

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[12] As Dawley states, one way to start is to post a tweet 'once a day at the very least, [...] and then pay attention to how followers react to find the frequency that works best for you' (2015: Post regularly section, para 2.).

DISCUSSION

Our results show that, although Twitter is included in the communication strategies of the SED and the APS, and the use of social media has increased over the years, there is room for improvement in terms of more effective use of Twitter as a communication tool with their audiences.

In relation to content, SED posted mostly profile tweets, whereas the APS tended to enter into more dialogue with its users (see Figure 1).[13] Although 'social media is distinguished from traditional broadcast and print media by its "user generated content"' (King et al. 2013: 291), in this case the SED is performing well because 'although user-generated content has important advantages, it may also lead to widespread sharing of poor quality information and material that is offensive to individuals or groups' (Syred et al. 2014: e108). In other words, user-generated content is often not verified by experts (Kind and Evans 2015). Nevertheless, in both cases most retweets originated in the Twitter profiles of health professionals and institutions.

Regarding the most recurrent topics, the two organizations tend to post too much institutional content and news-related tweets (see Table 1). The profiles are being used 'as another channel to distribute information rather than creating conversations and engaging with the audience' (Thackeray et al. 2012: 6). Both organizations tend to use their accounts as an appendix to their website rather than as a 2.0 communication tool with its own potentialities (Fallon and Schmalzried 2013). This 'notice board' use is harmful for both profiles. Finally, in relation to the presence of images, videos and links, there is room for improvement in both profiles (see Table 2). Our results coincide with those of Thackeray et al. (2012: 5), who reported that institutions 'are not capitalizing on social media's interactive potential'. Although interactivity allows health information to be more understandable (Park et al. 2011), neither the SED nor the APS took full advantage of this, as both link averages were below 1, which means that not every tweet contained a link.

Concerning interactivity, we report several results. Firstly, regarding retweets and likes, the SED was slightly more effective than the APS (see Table 4). Bray (2012: para. 4) says that 'the more followers you have, the more average retweets each of your tweets will get', which is not the case here. However, we do not know if the averages were high or low; as Dawley (2015: para. 2) points out, 'a million followers on Twitter won't be very useful if only two of them are engaging with your tweets on a regular basis'. In that sense, Bray (2012: para. 11) says that institutions should expect to get '1.3 retweets per 10,000 followers' from each tweet. Taking this figure as a benchmark, both profiles were above average in this regard.[14]

Second, the user interaction results for the two profiles were similar (see Table 3): on the one hand, the users interacted relatively little with the APS and the SED (seven of ten tweets did not inspire any user interaction). But on the other hand, if we deeply analyse the data, we observe that the APS replied more interactions from users than the SED (50.3% versus 17.6%, respectively). These numbers mean that even though users did not interact much with both profiles, at least the APS did more effort than the SED to engage with their audience.

Although the APS was more efficient in terms of hash tagging, averages were low for the two organizations (see Table 6). Generally, posted tweets had only one hashtag, but there were also tweets without hashtags (five out of

[13] 80.7% of the content posted by the SED are profile tweets, whereas in the case of the APS, it is only the 67.3% of its content. Profile tweets are unidirectional, so in this case, we suggest that the APS is interacting more with its users. This conclusion is reaffirmed with the user interactions results (see Table 3).

[14] Using Bray's (2012) formula, the SED average would have to be 0.4 retweets per tweet whereas the APS average would have to be one retweet per tweet.

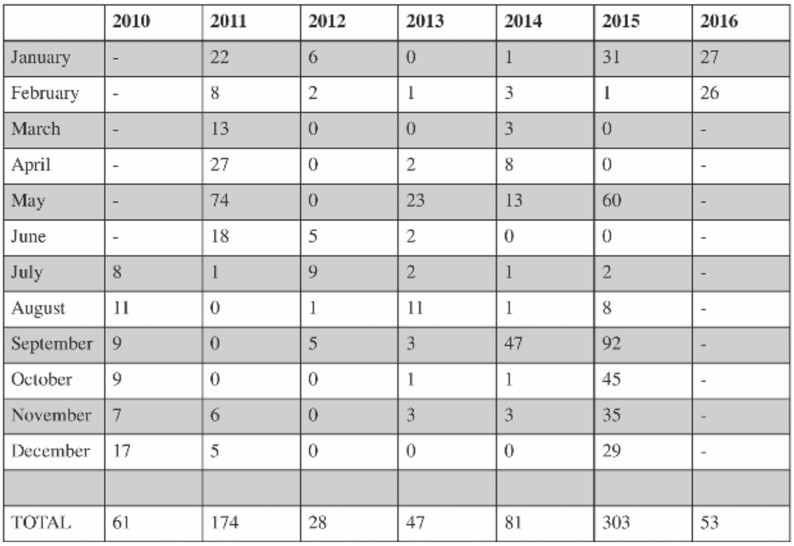
ten for the SED, and two out of ten for the APS). In both cases, the most used hashtags were pain-related, except for the #ReadByQxMD hashtag (see Table 5). Although the two profiles made limited use of this resource, they tended to use it properly and effectively.

Concerning targets, both profiles seemed to be working this aspect properly (see Table 7), as addressing most of their tweets to external targets is a good practice. For example, in emergency situations – like the H1N1 virus outbreak of 2009 – governmental health departments and similar invested effort in a communication campaign that had the result that 'more people joined one local health department's social networking pages, and those […] followers acted as "information ambassadors" who disseminated more information through their networks' (Park et al. 2011: 65). Also, by addressing content to external targets, institutions are inviting users to participate by answering tweets and generating debate (Thackeray et al. 2012).

Both profiles differed in terms of post frequency (Figure 3). Table 8 suggests that the APS does not appear to follow any specific rules about how or when to post tweets in its profile. Several months in each year went by wherein the APS did not share tweets. Failing to tweet inevitably leads to a loss in interest (Lardi 2013; Dawley 2015). Nevertheless, 2015 may represent a watershed, as there was an apparent change in APS strategy, reflected in far more frequent tweeting (although this would need to be confirmed by follow-up research in the coming years).

The SED, in contrast, was more constant regarding frequency, with tweets posted every month since the account was created (Table 9), although in some months several days did go by without a single tweet.

Finally, regarding pain-related tweets, the results state that the SED posted more tweets about pain than the APS. Nevertheless, 80% (*n*=1981) of the data analysed were pain-related tweets.



	2010	2011	2012	2013	2014	2015	2016
January	-	22	6	0	1	31	27
February	-	8	2	1	3	1	26
March	-	13	0	0	3	0	-
April	-	27	0	2	8	0	-
May	-	74	0	23	13	60	-
June	-	18	5	2	0	0	-
July	8	1	9	2	1	2	-
August	11	0	1	11	1	8	-
September	9	0	5	3	47	92	-
October	9	0	0	1	1	45	-
November	7	6	0	3	3	35	-
December	17	5	0	0	0	29	-
TOTAL	61	174	28	47	81	303	53

Table 8: Evolution in tweets posted by the APS.

	2010	2011	2012	2013	2014	2015	2016
January	-	-	-	-	91	64	22
February	-	-	-	-	43	13	13
March	-	-	-	0	77	34	-
April	-	-	-	9	44	25	-
May	-	-	-	31	95	100	-
June	-	-	-	53	32	41	-
July	-	-	-	36	63	53	-
August	-	-	-	31	54	12	-
September	-	-	-	30	84	33	-
October	-	-	-	101	24	33	-
November	-	-	-	97	46	51	-
December	-	-	-	60	34	98	-
TOTAL	-	-	-	448	687	557	35

Table 9: Evolution in tweets posted by the SED.

CONCLUSION AND FURTHER RESEARCH

Our results show that the APS and the SED are competent in aspects like pain-related tweets, targeted audiences, tweet typologies (especially the SED), use of hashtags (especially the APS) and certain interactivity components (retweets and likes). However, we suggest that improvements are necessary in areas such as frequency (especially the APS), tweet topics, number of user interactions (especially the SED) and the use of narrative content (images, videos and links). Both the SED and the APS profiles are at the *low engagement* stage, according to Neiger et al., characterized by 'one-way messaging from the organization to its followers' in that the organization 'does not ask for a response or for action but merely provides information' (2013: 159). In other words, the online presence needs to reflect more and better engagement.

In order to build a relationship whereby an organization engages actively with users, 'organizations need to […] develop strategies that are suitable, work out how often and when they should enter into conversations, and be aware of what others are doing and act accordingly' (Moorhead et al. 2013: e85). Besides, if health care institutions want to use social media effectively, they need to employ suitably qualified staff (Harris et al. 2013a; Thackeray et al. 2012; Fallon and Schmalzried 2013; Harris et al. 2013b).

The results of the analysis shows us that both the SED and the APS need to continue to improve the use of these resources,[15] because, in health, thanks to social media 'we all learn to be more sensitive to different points of view and more understanding of how to apply this awareness in our professional lives' (Daviss et al. 2015: 172). This is fundamental in the case of pain, where patients often feel isolated or stigmatized (Newton et al. 2013). The two institutions would, we suggest, benefit from developing a social media strategy so as to improve their effectiveness and impact in these new environments. Neiger et al. suggests that 'use of social media in health promotion should be valued for its potential to engage with audiences for enhanced communication and improved capacity to promote programs, products and services'

[15] The SED is not complying with its social media statement.

(Neiger et al. 2013: 162), but the results shows that neither SED nor APS are using this advantage.

This study is a first step in the way of finding out how pain is communicated through Twitter. As we suggested earlier, it is clear that social media are good tools for patients looking for a 'community' (Merolli et al. 2013; Moorhead et al. 2013; Mehta and Atreja 2015); but the results have shown us that both institutions are still not engaging with them. Nevertheless, regarding pain, we have only analysed if the content is pain or non-pain-related. One of the limitations of the study is that pain typologies were not considered for the analysis; and we suggest that additional studies should include this category on the analysis table, in order to understand deeply how pain is communicated via Twitter.

Finally, we used an exploratory methodology created specifically to analyse Twitter profiles for health care institutions, but further research is needed in order to test this new method of social media analysis in other studies of microblogging by health care institutions. Furthermore, we only considered the use of these technologies as a new way for pain organizations to communicate with their users and patients. Consequently, more data are needed in order to evaluate how institutional communication could promote social media among pain communities, and also to obtain more results regarding the reach and effectiveness of these tools in the health care and pain communication fields.

NOTES

A previous version of this article was presented at the 16th World Congress on Pain (Yokohama, Japan) and at the I Jornadas Nacionales de Comunicación en Salud (Elche, Spain).

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REFERENCES

Ahmad, Farah, Hudak, Pamela L., Bercovitz, Kim, Hollenberg, Elisa and Levinson, Wendy (2006), 'Are physicians ready for patients with Internet-based health information?', *Journal of Medical Internet Research*, 8: 3, e22.

Bray, Peter (2012), 'Justin Bieber gets 32K retweets per Tweet – can you beat that?', https://moz.com/blog/justin-bieber-and-you. Accessed 15 July 2016.

Breivik, H., Borchgrevink, P. C., Allen, S. M., Rosseland, L. A., Romundstad, L., Breivik Hals, E. K., Kvarstein, G. and Stubhaug A. (2008), 'Assessment of pain', *British Journal of Anaesthesia*, 101: 1, pp. 17–24.

Buchanan, Rachel and Beckett, Robert D. (2014), 'Assessment of vaccination-related information for consumers available on Facebook', *Health Information and Libraries Journal*, 31: 3, pp. 227–34.

Carrillo-Larco, Rodrigo M. (2012), 'Social networks and public health: Use of Twitter by ministries of health', *International Journal of Public Health*, 57: 4, pp. 755–56.

Chretien, Katherine C. and Kind, Terry (2013), 'Social media and clinical care: Ethical, professional, and social implications', *Circulation*, 127: 13, pp. 1413–21.

Chretien, Katherine C. and Tuck, Matthew G. (2015), 'Online professionalism: A synthetic review', *International International Review of Psychiatry*, 27: 2, pp. 106–17.

Cline, Rebecca J. W. and Haynes, K. M. (2001), 'Consumer health information seeking on the Internet: The state of the art', *Health Education Research*, 16: 6, pp. 671–92.

Cordón Benito, David and González González, Diana (2016), 'Museos y comunicación: los nuevos medios como herramienta de diálogo y sociabilidad de la institución. El uso de Twitter por el museo del Prado, museo Thyssen-Bornemisza y museo Reina Sofía', *Fonseca: Journal of Communication*, 12: 12, pp. 149–65.

Dann, Stephen (2010), 'Twitter content classification', *First Monday*, 15: 12, n.p.

Daviss, Steve, Hanson, Annette and Miller, Dinah (2015), 'My three shrinks: Personal stories of social media exploration', *International Review of Psychiatry*, 27: 2, pp. 167–73.

Dawley, Sarah (2015), 'How to attract and engage more Twitter followers', https://blog.hootsuite.com/how-to-get-twitter-followers/. Accessed 1 September 2016.

DeCamp, Matthew (2015), 'Ethical issues when using social media for health outside professional relationships', *International Review of Psychiatry*, 27: 2, pp. 97–105.

Facebook (2017), 'Instant articles: Frequently asked questions', https://developers.facebook.com/docs/instant-articles/faq?locale=en_US. Accessed 14 January 2017.

Fallon, L. Fleming and Schmalzried, Hans D. (2013), 'A study on the responsiveness of local health departments that use Facebook', *Journal of Homeland Security and Emergency Management*, 10: 1, pp. 201–08.

Federation of State Medical Boards (2013), 'Model policy on the use of Opioid Analgesics in the treatment of chronic pain', http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/FSMB_pain_policy_july2013.pdf. Accessed 16 September 2016.

Gausepohl, Shannon (2016), 'Twitter for business: Everything you need to know', http://www.businessnewsdaily.com/7488-twitter-for-business.html. Accessed 27 September 2016.

Gonzalez-Polledo, Elena (2016), 'Chronic media worlds: Social media and the problem of pain communication on Tumblr', *Social Media + Society*, January–March, pp. 1–11.

Gonzalez-Polledo, Elena and Tarr, Jen (2014), 'The thing about pain: The remaking of illness narratives in chronic pain expressions on social media', *New Media & Society*, 18: 8, pp. 1–18.

Harris, Jenine K., Mueller, Nancy L. and Snider, Doneisha (2013a), 'Social media adoption in local health departments nationwide', *American Journal of Public Health*, 103: 9, pp. 1700–07.

Harris, Jenine K., Mueller, Nancy L., Snider, Doneisha and Haire-Joshu, Debra (2013b), 'Local health department use of Twitter to disseminate diabetes information, United States', *Preventing Chronic Disease*, 10, n.p.

Hawn, Carleen (2009), 'Take two aspirin and tweet me in the morning: How Twitter, Facebook, and other social media are reshaping health care', *Health Affairs*, 28: 2, pp. 361–68.

Heldman, Amy B., Schindelar, Jessica and Weaver, James B. III (2013), 'Social media engagement and public health communication: Implications for public health organizations being truly "social"', *Public Health Reviews*, 35: 1, pp. 1–18.

Hesse, Bradford W., Nelson, David E., Kreps, Gary L., Croyle, Robert T., Arora, Neeraj K., Rimer, Barbara K. and Viswanath, Kasisomayajula (2005), 'Trust and sources of health information. The impact of the internet and its implications for health care providers: Findings from the first health information national trends survey', *Archives of Internal Medicine*, 165: 22, pp. 2618–2624.

Househ, Mowafa (2013), 'The use of social media in healthcare: Organizational, clinical, and patient perspectives', in K. L. Courtney, O. Shabestari and A. Kuo (eds), *Enabling Health and Healthcare through ICT*, IOS Press BV: Amsterdam, pp. 244–48.

Huertas, Assumpció and Mariné, Estela (2014), 'Uso y utilidades de las herramientas de análisis online para la evaluación de la comunicación de las marcas de destino a través de los social media', *Sphera Publica*, June, pp. 117–34.

Huguet, Anna, Miró, Jordi and Nieto, Rubén (2009), 'The factor structure and factorial invariance of the Pain-Coping Questionnaire across age: Evidence from community-based samples of children and adults', *European Journal of Pain*, 13: 8, pp. 879–89.

Jackson, Jean E. (2005), 'Stigma, liminality, and chronic pain: Mind-body borderlands', *American Ethnologist*, 32: 3, pp. 332–53.

Kilaru, Austin S., Asch, David A., Sellers, Allison and Merchant, Raina M. (2014), 'Promoting public health through public art in the digital age', *American Journal of Public Health*, 104: 9, pp. 1633–35.

Kind, Terry and Evans, Yolanda (2015), 'Social media for lifelong learning', *International Review of Psychiatry*, 27: 2, pp. 124–32.

King, Dominic, Ramirez-Cano, Daniel, Greaves, Felix, Vlaev, Ivo, Beales, Steve and Darzi Ara (2013), 'Twitter and the health reforms in the English National Health Service', *Health Policy*, 110: 2–3, pp. 291–97.

Korda, Holly and Itani, Zena (2013), 'Harnessing social media for health promotion and behavior change', *Health Promotion Practice*, 14: 1, pp. 15–23.

Lafferty, Natalie T. and Annalisa, Manca (2015), 'Perspectives on social media in and as research: A synthetic review', *International Review of Psychiatry*, 27: 2, pp. 85–96.

Lardi, Kamales (2013), 'The social media strategy framework', in K. Lardi and R. Fuchs (eds), *Social Media Strategy*, Zürich: vdf Hochschulverlag AG an der ETH Zürich, pp. 17–46.

Lardi, Kamales and Ledergerber, Armin (2013), 'Plan and deliver Business 2.0 Initiatives', in K. Lardi and R. Fuchs (eds), *Social Media Strategy*, Zürich: vdf Hochschulverlag AG an der ETH Zürich, pp. 67–94.

Leigh, Jessica (2015), 'Living with invisible illness', http://www.theatlantic.com/health/archive/2015/07/invisible-illness-chronic-disease-fibromyalgia/398393/. Accessed 18 September 2016.

Lesemann, Mara (2016), 'How Google and Twitter compete with Facebook's instant articles', http://www.investopedia.com/articles/markets/012116/how-google-twitter-compete-facebooks-instant-articles-fb-googl.asp. Accessed 14 January 2017.

Mann, Eileen M. and Carr, Eloise C. J. (2009), *Pain. Creative Approaches to Effective Management*, New York: Palgrave Macmillan.

Mayo Clinic Staff (2014), 'Fibromyalgia: Understand the diagnosis process', http://www.mayoclinic.org/diseases-conditions/fibromyalgia/in-depth/fibromyalgia-symptoms/art-20045401. Accessed 18 September 2016.

Mehta, Neil and Atreja, Ashish (2015), 'Online social support networks', *International Review of Psychiatry*, 27: 2, pp. 118–23.

Merolli, Mark, Gray, Kathleen and Martin-Sanchez, Fernando (2013), 'Developing a framework to generate evidence of health outcomes from social media use in chronic disease management', *Medicine 2.0*, 2: 2, e3.

Mesko, Phyllis J., Elliades, Aris B., Christ-Libertin, Cheryl and Shelestak, Debra (2011), 'Use of picture communication aids to assess pain location in pediatric postoperative patients', *Journal of Perianesthesia Nursing*, 26: 6, pp. 395–404.

Moorhead, Anne, Hazlett, Diane E., Harrison, Laura, Carrol, Jennifer K., Irwin, Anthea and Hoving, Ciska (2013), 'A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication', *Journal of Medical Internet Research*, 15: 4, e85.

Neiger, Brad L., Thackeray, Rosemary, Burton, Scott H., Giraud-Carrier, Christophe and Fagen, Michael C. (2013), 'Evaluating social media's capacity to develop engaged audiences in health promotion strategies: Use of Twitter metrics as a case study', *Health Promotion Practice*, 14: 2, pp. 157–62.

Neira, Fernando (2013), 'La nueva página web de la SED', http://portal.sedolor.es/pagina/index.php?id=191. Accessed 9 September 2016.

Newton, Benjamin J., Southall, Jane L., Raphael, Jon H., Ashford, Robert L. and LeMarchand, Karen (2013), 'A narrative review of the impact of disbelief in chronic pain', *Pain Management Nursing*, 14: 3, pp. 161–71.

NIH Medline Plus (2011), 'Chronic pain: Symptoms, diagnosis, & treatment', *NIH Medline Plus the Magazine*, 6: 1, pp. 5–6.

Park, Hyojung, Rodgers, Shelly and Stemmle, Jon (2011), 'Health organizations' use of Facebook for health advertising and promotion', *Journal of Interactive Advertising*, 12: 1, pp. 62–77.

—— (2013), 'Analyzing Health organizations' use of Twitter for promoting health literacy', *Journal of Health Communication: International Perspectives*, 18: 4, pp. 410–25.

Robillard, Julie M., Johnson, Thomas W., Hennessey, Craig, Beattie, B. Lynn and Illes, Judy (2013), 'Aging 2.0: Health information about dementia on Twitter', *PLoS ONE*, 8: 7, e69861.

Scanfeld, Daniel, Scanfeld, Vanessa and Larson, Elaine L. (2010), 'Dissemination of health information through social networks: Twitter and antibiotics', *American Journal of Infection Control*, 38: 3, pp. 182–88.

Seymour, Brittany, Getman, Rebekah, Saraf, Avinash, Zhang, Lily H. and Kalenderian, Elsbeth (2015), 'When advocacy obscures accuracy online: Digital pandemics of public health misinformation through an antifluoride case study', *American Journal of Public Health*, 105: 3, pp. 517–23.

Sosnowy, Collette (2014), 'Practicing patienthood online: Social media, chronic illness, and lay expertise', *Societies*, 4: 2, pp. 316–29.

Syred, Jonathan, Naidoo, Carla, Woodhall, Sarah C. and Baraitser Paula (2014), 'Would you tell everyone this? Facebook conversations as health promotion interventions', *Journal of Medical Internet Research*, 16: 4, p. e108.

Thackeray, Rosemary, Neiger, Brad L., Smith, Amanda K. and Van Wagenen, Sarah B. (2012), 'Adoption and use of social media among public health departments', *BMC Public Health*, 12: 242, n.p.

Torkkola, Sinikka (2013), 'Health communication in social media 2011–2015', http://www.uta.fi/cmt/tutkimus/comet/yhteystiedot/torkkola/english/healthcommunication.html. Accessed 8 September 2016.

—— (2016), 'Multifaced Health Communication', in V. Marinescu and B. Mitu (eds), *Health and the Media: Essays on the Effects of Mass Communication*, Jefferson: McFarland and Company Inc., pp. 17–36.

Torre-Díez, Isabel De la, Díaz-Pernas, Francisco J. and Antón-Rodríguez, Miriam (2012), 'A content analysis of chronic diseases social groups on Facebook and Twitter', *Telemedicine and e-Health*, 18: 6, pp. 404–08.

van Dijck, José (2013), *The Culture of Connectivity. A Critical History of Social Media*, New York: Oxford University Press.

Walsh, Joseph, Eccleston, Christopher and Keogh, Edmund (2014), 'Pain communication through body posture: The development and validation of a stimulus set', *Pain*, 155: 11, pp. 2282–90.

Weiner, John (2015), 'A personal reflection on social media in medicine: I stand, no wiser than before', *International Review of Psychiatry*, 27: 2, pp. 155–60.

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4.4 Study III

Communicating the experience of pain through social media: patients' narrative practices on Instagram

Communicating the experience of pain through social media: patients' narrative practices on Instagram

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ABSTRACT

Background: At a time when medicine is advancing by leaps and bounds, pain communication remains a difficult puzzle to solve. Given the problems of communication in patient-physician interactions, individuals have found in social media a new way to talk about their pain experience. Method: This study analyzes patients' pain communication practices on Instagram. Through a qualitative examination of 350 Instagram posts that were selected via a multistage sampling strategy, our goal was to identify how and why pain patients carry out these narrative practices on this platform. Results: Instagram is making visible illnesses, such as fibromyalgia or endometriosis, which tend to encounter disbelief in real life. Our patients talk about their pain experience in terms of chaos and use narratives to construct a world where pain episodes acquire meaning. However, men are largely absent of these online practices since most of the publications analyzed were shared by women (94%, n=329). Moreover, pain communication practices in social media are discussed in terms of a three-way process (breaking-reenactment-result). Conclusion: Health-related institutions could improve pain management by paying more attention to these patient self-expression practices. It is pointed to how social media (and particularly, Instagram) are changing the way sufferers live with their chronic pain.

Keywords: Instagram; chronic pain; self-expression; patients; illness narratives; social media; pain communication; health communication

BACKGROUND

Pain is a complex experience that each person constructs in different ways [1,2]. This condition, which often relates to the disbelief of others, leads patients to encounter isolation, stigma, and emotional distress on a recurring basis [3]. Moreover, those who suffer from it have to prove repeatedly that they are "in constant pain" [4, p.4]. As Steinkopf argues, "making pain credible can take time in real life. People with chronic pain are in a completely different communicative situation when they complain about their pain toward their peers or towards a physician" [5, p.5]. In consequence, patients frequently feel isolated and ashamed before their families and in front of their health professionals [2,6].

At the same time, pain is much more than a medical disorder. This condition also affects patient's daily lives, because "the undercurrent of chronic illness is like the volcano: it does not go away" [4, p.44]. This means that some aspects related to pain management, like attending a medical appointment, are also part of the patient's problems. In this sense, Kleinman points out that "enormous blocks of time are spent travelling to and from clinics, sitting and standing in doctors' office, undergoing laboratory tests, lying in hospital beds, waiting" [4, p.46]. As a result, chronic pain sufferers experience a lack of control over the illness that affects their identities [7,8].

Furthermore, pain also relates to uncertainty. According to Brashers, "complications of health status, such as ambiguous symptoms, unclear diagnosis (…) or lack of information on treatment options, can create uncertainty about financial well-being, the social reactions of others, and future changes in health status" [9, p.480]. Given this situation, and taking into account the multiple factors that influence the pain experience, patients feel the need to express what happens to them. As Ressler et al. suggests, "communicating the experience of pain and illness may facilitate sharing between teller and listener, allow for reflection on the experience, and acknowledge the emotional and suffering component of pain" [10, p.e143].

This process, known as pain communication [5], can occur in different ways. Traditionally, physicians have used questionnaires to help patients to express their pain [11], but the communication of this condition can also take place through illness narratives. According to Kleinman [4] and Hydén [12], the use of this technique allows patients to explain pain in new ways. For instance, narratives can be used "to construct an illness experience, to reconstruct life history, to make disease and illness understandable, and to collectivize illness experience" [12, p.64]. Besides, as every pain episode generates a disruption that breaks the timeline of the sufferer, "narratives offer an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework" [12, p.53]. However, lack of time in patient-physician interactions makes difficult the use of these narratives for pain communication [13].

In response, patients have found in social media the space to express their concerns. On the one hand, these platforms permit to create virtual support spaces where those who suffer from pain can discuss their stories with other peers [10,14]. On the other hand, pain is visible again in social media, which decreases the perception of isolation of the patient [2,10,15,16]. As a result, these platforms are becoming basic tools for those affected by chronic pain [10,17], because they "invite us to think of pain not as a one-off, catastrophic life-changing event, but as a way of being in the world with a difference" [2, p.2]. After all, with this narrative-sharing practice, "the teller of an illness story seeks to learn the true name of the disease" [18, p.75–76]. The objective of this research is to analyze how and why patients carry out this process of pain communication in social media platforms.

As previous studies have already analyzed the importance of sites like Tumblr, Flickr or Facebook for pain communication [2,19,20], as well as the relevance of sites like Twitter for different chronic pain organizations [21], this research examined patient narrative practices on Instagram. This site characterizes for being a visual social media platform [22], which means that users always have to share an image with their publication[i]. As sometimes pain is difficult to express in words [23], the use of visual elements could help patients to improve the communication of their pain. Likewise, as Pittman and Reich suggest, "image-based platforms such as Snapchat and Instagram confer to their users a significant decrease in self-reported loneliness" [24]. Since pain also relates to isolation, Instagram becomes a platform of interest to study in the context of chronic pain. Moreover, this site is now more popular than Facebook or Twitter [22,25], and people with chronic illnesses are more open to discuss their feelings on this platform instead of talking with their physicians [14]. Therefore, given the significance of Instagram for pain patients, the following research questions (RQ) were raised:

> RQ1: Which illness narratives are using chronic pain sufferers on Instagram, and how they are using these stories?
>
> RQ2: Which are the most mentioned pain-related illnesses in Instagram posts, and in what way patients visually represent themselves in these publications?
>
> RQ3: Who shares these posts, and which level of engagement these publications are generating?

At the same time, narratives are polymorphic [26]. This assumption means that some authors consider illness narratives as the main genre from which different subgenres emerge, like cancer or AIDS narratives [6,26]. As Ong et al. argues, "research on pain must pay close attention to the words chosen by those who are in pain to describe their experiences" [27, p.533]. In this sense, since pain has its own particularities, pain narratives can also be considered a subgenre of illness narratives with additional self-expression needs [6,28,32,37]. Accordingly, a last research question (RQ) was raised:

> RQ4: Which pain narratives are the most used by chronic pain patients on Instagram, and what characteristics these stories present?

MATERIAL AND METHODS

Using the Netlytic[ii] software [29], a week of Instagram publications (27th February to 5th March 2017) tagged with the #chronicpain hashtag was captured, obtaining a total sample of 21760 posts (Table 1). Every hour, this program retrieves from the platform the last 100 publications, but does not distinguish duplicate posts. The first step was to remove all these repeated links manually, reducing the initial sample to 7726 posts. Hereunder, in order to be able to apply a qualitative analysis to the sample, the number of cases collected was reduced following a multistage sampling strategy [30].

Table 1. Sampling registers.

Date	Registers	Without duplicates
02/27	3181	1043
02/28	3467	1283
03/01	3416	1222
03/02	3268	1151
03/03	2680	1039
03/04	3045	952
03/05	2703	1036
Total	**21760**	**7726**

This process of multistage sampling [30] started with data stratification by day, following Rose's [31] study on content analysis of visual images. Then, a criterion-i strategy[iii] [30] was used to randomly select 50 posts per day. These publications were chosen according to the following criteria: (a) posts must be personal; (b) posts must tell a story about pain; (c) posts must have both text and image; (d) posts must be shared using two (or more) pain-related hashtags; and (e) posts must not be commercial. After completing this procedure, a final sample of 350 posts[iv] was obtained. In the last instance, publications were coded manually into different categories using an Excel file, in accordance with illness narrative studies [6–8,12,18,32–38] and communication and uncertainty studies [9]. Figure 1 depicts the sampling process used.

Figure 1. Sampling process

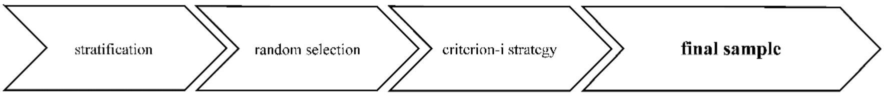

Table 2. Assignment of the categories.

Research question	Categories assigned
RQ1: Which illness narratives are using chronic pain sufferers on Instagram, and how they are using these stories?	(1) illness narrative typology [18] (2) use of the illness narrative [12]
RQ2: Which are the most mentioned pain-related illnesses in Instagram posts, and in what way patients visually represent themselves in these publications?	(3) kind of pain (typologies) (4) kind of visual representation used (typologies) (5) photographic frame of the persons depicted [7,8]
RQ3: Who shares these posts, and which level of engagement these publications are generating?	(6) gender of the owner of the profile (7) number of likes (8) number of comments
RQ4: Which pain narratives are the most used by chronic pain patients on Instagram, and what characteristics these stories present?	(9) pain narrative typology [6,32] (10) coping strategy [35] (11) level of uncertainty [9,37,38] (12) use of metaphors to express illness/pain [33,34,37] (13) references to health professionals [36] (14) level of private information sharing [38]

The categories selected to code the posts were the following: (1) illness narrative typology; (2) use of the illness narrative; (3) kind of pain (typologies); (4) kind of visual representation used (typologies); (5) photographic frame of the persons depicted; (6) gender of the owner of the profile; (7) number of likes; (8) number of comments; (9) pain narrative typology; (10) coping strategy; (11) level of uncertainty; (12) use of metaphors to express illness/pain; (13) references to health professionals; and, finally, (14) level of private information sharing [6–9,12,18,32–38]. Prior to data analysis, these categories were assigned to each one of the research questions (Table 2).

RESULTS

Research question one

The first question of this study (RQ1) asked for which illness narratives were using chronic pain sufferers on Instagram and how they were using these stories. To answer this question, we coded the posts according to categories 1 and 2 (Table 2). Regarding the typology of illness narratives (category 1), Frank suggests that these can be classified as restitution (health recovery); chaos (health deterioration); or quest (the purpose of being ill) [18]. In the 350 publications analyzed, the majority of patients used **narratives of chaos**[v] (73.1%, n=256) to discuss their pain (Table 3). A priori, the use of this narrative adjusts to the reality of chronic pain patients, because "the chaos story presupposes lack of control" [18, p.100]. Likewise, this finding suggests that illness narratives occupy a different scenario in social media, given that medicine and health-related institutions have always favored restitution stories [18]. Nevertheless, like in the case of pain, this institutionalized narrative "no longer works when the person is dying or when impairment will remain chronic" [2, 18, p.94].

Concerning the use of the illness narrative (category 2), Hydén [12] suggest that they can be applied in the following ways:

> 1. to transform illness events and construct a world of illness; 2. to reconstruct one's life history in the event of a chronic illness; 3. to explain and understand the illness; 4. as a form of strategic interaction in order to assert or project one's identity; and lastly, 5. to transform illness from an individual into a collective phenomenon. [p.55]

Table 3. Results of the analysis per categories.

Codes	Categories	Posts	Percentage
(1)	Illness narrative typologies		
	Restitution	35	10.0
	Chaos	256	73.1
	Quest	59	16.9
(2)	Use of the illness narratives		
	Construction of an illness world	205	58.6
	Reconstruction of life history	16	4.6
	Explanation/understanding of illness	55	15.7
	Strategic device	55	15.7
	Transformation to a collective experience	19	5.4
(4)	Visual representations		
	Photo	219	62.6
	Illustration	125	35.7
	Boomerang[a]	1	0.3
	Video	5	1.4
(5)	Photographic frames		
	Face/face and body	108	30.8
	Body/body part	30	8.6
	Other (treatment, meme, etc.)	87	24.9
	No frame (illustration, etc.)	125	35.7
(9)	Pain narrative typologies		
	Generalization	155	44.3
	Deletion	169	48.3
	Distortion	26	7.4
(10)	Coping strategies		
	Problem-focused	102	29.1
	Emotional-focused	243	69.5
	Avoidance-focused	5	1.4
(11)	Level of uncertainty		
	Negative	116	33.1
	Positive	61	17.5
	Neutral	41	11.7
	Combined	132	37.7
(14)	Private information sharing		
	Low	158	45.2
	Medium	95	27.1
	High	97	27.7

Note. Within each category, the sum of the posts is n=350 and the sum of the percentage is n=100.

[a] Boomerang refers to the Instagram feature that permits users to record video loops.

Altogether, the posts analyzed show that patients mostly used the narratives to construct an **illness world** (58.6%, n=205) (Table 3). Since "illness soaks up personal and social significance from the world of the sick person" [4, p.31], this result also makes sense in the context of chronic pain. According to this finding, patients are using these publications to construct their world of illness each time a pain episode disrupts their timeline [12]. Besides, as narratives "help explicate the predictable uncertainties implicit in pain" [37, p.737] and contribute to creating "meanings, direction and common shared belief in [healthcare] innovation processes" [39, p.247], pain sufferers construct their own world as a way of giving meaning to their pain experience [7,12].

Research question two

RQ2 searched which were the most mentioned pain-related illnesses in Instagram posts and in what way patients visually represented themselves in these publications. On this occasion, posts were coded according to categories 3–5 (Table 2). As for the types of pain (category 3), users discussed up to 79 different conditions in the 350 Instagram posts analyzed (Figure 2). The most mentioned pain-related illnesses in the publications were **fibromyalgia** and **endometriosis** (with 88 and 65 references, respectively), followed by arthritis (51), Ehlers Danlos Syndrome (EDS) (44) and migraines (35)[vi].

Figure 2. Word cloud of mentions in the posts on different illnesses.

This finding is hardly surprising. In the healthcare system, the two illnesses most discussed in the posts (fibromyalgia and endometriosis) are usually difficult to diagnose [40,41], and patients' who suffer from these conditions "fight to be taken at their word" [42, par.8] on a recurring basis. Moreover, fibromyalgia, considered by many an invisible illness, is especially tricky since existing tests are unable to confirm the presence of this ill-condition [40,42]. In this sense, as Newton et al. suggest, "those with fibromyalgia [traditionally] hide their diagnosis (…) in an attempt to control the stigma and disbelief they can face from others" [3, p.167].

Regarding the way chronic pain sufferers visually represented themselves in Instagram, we analyzed both the visual portrayals chosen by these patients in the publications (category 4) and the photographic frame of the persons depicted in the images (category 5). On the one hand, the majority of pain sufferers selected **pictures**[vii] (62.6%, n=219) as visual representations of their posts (category 4, Table 3). On the other hand, the most recurrent photographic frame in these images were the **face** or **face and the body** (30.8%, n=108) of the person who appears in the photograph (category 5, Table 3). As indicated above, chronic illness produces multiple breakups in the life course of a patient [7,12], and individuals often lose the sense of their identity [7,8,32]. In other words, patients experience pain in a fragmented way. According to these results, it seems that the communication of this pain is also divided into pieces, since patients focus only on a part of their bodies to illustrate their pain.

Additionally, the most common practice for users is sharing a photograph of their face to better illustrate the expression of pain. Previous studies have found how patients use selfies as a way of representing an invisible illness on social media [2]. Concerning this, Goffman explains that individuals tend to present themselves favorably to others because people treat them according to first impressions [8]. Considering that "people in pain are judged to be (…) less likeable" [5, p.3], results suggest that patients express their pain with images of their faces in order to reassert that they are still the same despite their illness.

Research question three

The third question of this study (RQ3) asked for who was sharing these posts and which level of engagement these publications could generate. In order to obtain a response, posts were coded according to categories 6–8 (Table 2). Concerning the gender of the owner of the profile (category 6), results show that posts were mostly shared by women (94%, n=329). Moreover, if we look at the gender of persons depicted in the images analyzed, women are also in the majority (37.7%, n=132). Taking into account the two pain-related illnesses most mentioned in the publications (category 3), this finding is hardly surprising, since endometriosis only affects women, and fibromyalgia affects seven times more women than men [40,43]. As for the level of engagement that these publications were generating, we looked at the number of likes (category 7) and the amount of comments (category 8) referring to the posts in our sample. In the results appears that publications had an average of **4.1 comments** and **58.3 likes** per post.

Research question four

RQ4 asked for which pain narratives were the most used by chronic pain patients on Instagram and what characteristics these stories present. Here, posts were coded according to categories 9–14 (Table 2). Regarding the typology of pain narratives (category 9), Johnson and Hudson argue that patients can describe pain events by generalizing information (using one episode to define the entire illness-related experience), deleting information (focusing only on certain aspects of an illness), or by distorting information (misreading illness-related information) [32]. In the 350 Instagram posts analyzed, patients used both **deletion** (48.3%, n=169) and

generalization (44.3%, n=155) narratives to discuss about their pain (Table 3). This finding suggests that sufferers are using these publications to talk only about their bad experiences, a result that makes sense in the context of chronic pain since this condition entails constant problems and disbelief [3,4]. Likewise, this result reaffirms the problem of pain communication in patient-physician interactions, because the use of these deleted and generalized narratives involves a reflection on how "diagnoses and pain management solutions […] offered by practitioners may be misinterpreted by pain patients as judgments on their beliefs, values and sense of self" [32, p.412–413].

Concerning the characteristics that these stories present, the research focused on analyzing the coping strategy used in the publications (category 10) as well as the level of uncertainty of the narrative (category 11), the use of metaphors (category 12), the number of references to health professionals (category 13), and the level of private information disclosed (category 14). In terms of the coping strategy used in the narratives (category 10), Kohn (cited by

Wright et al. [35]) suggests that they can be classified into three types: problem-focused (aimed at finding solutions), emotional-focused (the illness overcomes the patient), and avoidance-focused (keeping away from danger). The results of the analysis show that the majority of patients made clear use of the **emotional-focused coping strategy** (69.5%, n=243) in their stories (Table 3). Considering that having a chronic illness is a recurring experience with clearly emotional components [4], the use of this coping strategy fits the reality of chronic pain patients. Likewise, since this strategy "refers to behaviors such as venting frustrations about a stressful situation or expressing some type of emotional response to it rather than making an attempt to remedy or improve the situation" [35, p.82], this finding suggests that pain sufferers use it in their publications as a way to look for support on Instagram [10,14].

As for the level of uncertainty (category 11), Brashers suggests that patients respond in one of four ways: negative (uncertainty is risky), positive (uncertainty is beneficial), neutral (uncertainty is neither risky nor beneficial), or combined (uncertainty results both positive and negative responses) [9]. According to findings reached, the level of uncertainty of the narratives tends to be **combined** (37.7%, n=132) or **negative** (33.1%, n=116) (Table 3). This result indicates that posts contain both stories where patients do not see a positive development of their illnesses (negative uncertainty) and stories where patients are confident about their future even despite all their problems (combined uncertainty) [9]. Since "chronic illnesses tend to oscillate between periods of exacerbation, when symptoms worsen, to periods of quiescence, when disability is less disruptive" [4, p.7], the existence of this duality makes sense in the context of chronic pain. Moreover, as "pain is a magnet for complications and uncertainties" [37, p.735–736], doubts (even if its levels vary) are always present in the stories of pain sufferers.

In relation to the use of metaphors (category 12) and the number of references to health professionals (category 13), findings show that users generally **did not use metaphors** to communicate suffering (94.6%, n=331) and made **very little reference** to healthcare staff

(86.6%, n=303). On the one hand, metaphors tend to simplify complex stories [33]. This means that chronic pain is perceived as less threatening if patients use metaphors to talk about their problems. Therefore, it is suggested that sufferers do not use these figures of speech in their publications to avoid simplifying the pain experience. Even beyond, previous studies corroborate that patients' stories usually have a lack of references to health professionals [36]. In a narrative analysis of YouTube videos created by cancer survivors, Chou et al. found that healthcare staff was "infrequently mentioned and depersonalized" in the stories of the patients [36, p.e7]. In this sense, although physicians and other health professionals form an important part of the illness puzzle, pain remains an intimate experience [16].

Lastly, regarding the level of private information disclosed (category 14), within the study the publications have been analyzed according to three information sharing levels: low (only the illness or pain is mentioned), medium (minor details of the treatment or medication are revealed), and high (practically the entire medical record is shared). As Table 3 shows, almost half of the patients revealed **low levels** of private information (45.2%, n=158) in their publications. This finding explains that patients do not usually share many personal details in single posts. However, if the full profile of these users was being analyzed, the level of online sharing of intimate experiences would be much higher than individually observed. In this sense, it should be taken into consideration that these pain communication practices are carried out by users who feel comfortable to making visible the pain they are suffering [19].

DISCUSSION

In the whole, pain communication practices by patients have been analyzed on social media, particularly Instagram. As results show, almost 3 out of 4 Instagram posts contain stories formed from chaos, and the majority of those who suffer from pain are using these narratives to construct their illness world (RQ1). Even beyond, it is inferred that patients are employing this platform as a way of fighting against the status quo. As stated above, health-related institutions have traditionally rejected chaos stories, because these narratives do not contemplate the option of being healthy again [18]. Considering that in social media people with chronic pain have regained the control thanks to explaining problems in their own way [2], Instagram has become a popular space to share and showcase these stories of chaos.

At the same time, the construction of the illness world enables patients to deal with the disbelief culture [3]. In other words, by using the posts to construct this world of illness, pain patients become "legitimately ill in the eyes of others" [3, p.164] because the publications are a proof of their suffering. But, is this world accessible to non-spoonies[viii]? According to Gonzalez-Polledo and Tarr, social media "offer opportunities for people without pain to better understand the experience of having pain" [19, p.1468]. However, patients turn to these spaces looking for the support of people who share their illness, because they are the ones who truly understand them [10,14]. In this regard, there is the possibility that pain patients are isolating themselves even further from others by creating these "spoonie worlds" — or "pain worlds" [2] — in social media.

Secondly, patients are mostly employing Instagram to increase the visibility of their illnesses [2], and to communicate their pain in a fragmented way by using images (RQ2). On the one hand, this platform is a game changer for patients with fibromyalgia and endometriosis, since visibility is another way to help sufferers to decrease their feeling of disbelief [10,15]. On the other hand, this fragmented communication of the illness on Instagram is used to cope with pain, because "the possible tensions between different variants of a disease disappear into the background when these variants are distributed over different sites" [44, p.115]. Besides, when patients choose to frame their faces in these photographs, it is when they are presenting themselves as their truest selves [8]. In this sense, it seems that this finding reflects the problems of patient-physician interactions.

Thirdly, the obtained results show that women share 9 out of 10 pain posts on Instagram and that these publications are generating different levels of engagement (RQ3). As stated above, this group is more affected by the illnesses that users discuss mainly on this platform. However, this finding may not be generalizable for the entire population. Depending on the gender, pain affects one way or another [45]. In this sense, women "are more likely to marshal a variety of resources-coping skills, support, and distraction-with which to deal with their pain" [45, par.2], like sharing their illness stories on Instagram. The fact that men do not talk about their pain in the 350 publications analyzed does not mean that they do not suffer from it. Concerning the levels of engagement of these publications, this research only looked at the average of comments and likes per post. Future studies should analyze more deeply the role of social media comments and its implications for pain communication.

On the other hand, when analyzing the publications from the perspective of pain narratives, we have found that many patients express this condition in terms of doubts and negative experiences. Besides, their stories have a clear emotional component, but sufferers do not mention health professionals in their publications nor use metaphors to discuss their pain. At the same time, these posts usually disclose low levels of patients' private information (RQ4). According to these findings, sites like Instagram are a new way of "communicating pain within and beyond clinical contexts" [19, p.1455] and, in particular, this platform has become a place where patients look for a positive response to their suffering. For instance, the use of deleted and generalized narratives (category 9) permits users to "survive […] the information overload of modern society" [32, p.412]. However, these results also point to some of the current problems of pain management.

In this regard, health organizations should consider the lack of references to their staff in the narratives of the patients as a warning sign. This practice seems to be related to the stigma of having pain [3,46], since sufferers are often disbelieved when telling their story to health professionals. By not including them in their narratives, patients are both emphasizing the intimacy of their pain and blocking the memory of the stigmatization experienced. Nevertheless, this practice increases the communication gap of patient-physician interactions. Likewise, the revelation of patients' private information is also an important concern. In a balanced way, pain sufferers seem to leave aside their intimacy on Instagram, because this platform is offering them visibility, credibility and support. Although that this information "is intentionally disclosed to others" [47, p.48], this practice also entails a risk [21]. Since patients will keep using social media platforms for pain communication, privacy is one of the key challenges that health organizations should address in the near future [38].

Lastly, as Table 1 shows, this study found that there are many posts on Instagram referring to chronic pain. This fact could be associated with the concept of genesis developed by Williams [7]. According to this author, this event takes place each time an illness disruption occurs. Since patients generate a new post on Instagram with each pain interruption; each new publication results in a new genesis for the sufferer. This research offered a preliminary exploration of how these posts generated from these events are a promising laboratory of research for pain communication analysis.

CONCLUSION

Considering the results observed in this study, pain communication on social media works as a three-way process. This procedure consists of a breaking phase, followed by a reenactment phase and, lastly, a result phase. Firstly, the **breaking phase** refers to the implications of chronic pain. As stated above, this includes disbelief, constant problems, lack of control and uncertainty about the future [3,4,9]. In contrast with the situation in the pre-Internet era, when pain communication only took place at the doctor's office or within families [2,10], these difficulties motivate patients to use platforms like Instagram to express their concerns.

Secondly, the **reenactment phase** refers to how those who suffer from pain carry out these self-expressions practices; that is, how patients choose to tell their story. Lastly, the **result phase** refers to the post shared by the user in these social media sites, marking the end of the process of self-expression. This procedure takes place each time a patient decides to share a pain-related publication on social media.

When individuals communicate their pain on these platforms, they fight against the problems entailed by chronic pain. Moreover, given that health-related organizations cannot provide the support they need, patients also seek the potential relief of expressing themselves in these online environments. As Han and Wiley point out, "illness narratives posted onto a social networking site creates connectivity needed by a patient who seeks to articulate and make sense of his or her health experience" [48, p.50]. In this regard, this study shows that Instagram is becoming a new space of support for those who suffer from pain [14]. Nevertheless, healthcare institutions need to take part as well of this process of pain communication. For instance, they should consider including these online narratives as part of pain assessment. According to Keim-Malpass et al., this would be beneficial for patients, since it would allow "a view that is often unavailable because of potentially high levels of distress and burden that traditional studies may place on participants and families" [17, p.215]. But, to serve as an adequate assessment tool, this form of self-reported experience needs to be a part of a larger structure [16]. The fact remains that "not all doctors are jazzed by patients who rely on social media to understand and express their illnesses" [14, par.10].

FURTHER RESEARCH

In this preliminary exploration of how patients communicate their pain through Instagram, the results show that practices of self-expression are networked [49], but only between and among patients. As reported elsewhere, healthcare organizations are interacting very little with patients on social media [50]. Future studies should explore how pain communities can be connected through social media platforms, as a possible solution to address the problem of pain communication in patient-physician interactions.

One limitation of this study is related to the image analysis. Although images and text were analyzed together, our research focused on practices of self-expression. Considering that photographs are a form of self-representation [8], further research is required to examine the significance of the images in depth. Likewise, the gender of posters and its possible relation to pain communication also requires more detailed analysis, as mentioned earlier. Moreover, our initial data analysis included the age of the users as a category for classifying the publications, but it was discarded since few individuals revealed this information in the posts analyzed. In this sense, care must be taken when generalizing the results of this variable for the entire population, because Instagram is popular mainly within younger individuals [51].

The last and not least, Instagram and other social media sites have permit patients to express and share their pain experiences in a new way, making them feel empowered. In these platforms, not only sufferers have a voice, but they can also make their pain visible again [2]. Concurrently, such self-expression practices reflect a change in how we understand the experience of individuals living with their own illnesses. As Han and Wiley point out, "when traditional 'Illness Narratives' (…) become interactive and conversational in a digital platform, the self-expression and connectivity taking place in an on-line social community contribute immensely to the patient's health journey" [48, p.47]. In this regard, healthcare institutions are forced to explore sooner than later how they will adapt to this changing environment inside which patient-physician interactions are immersed.

REFERENCES

[1] Craig KD. Social communication model of pain. Pain. 2015;156(7):1198–1199.

[2] Gonzalez-Polledo E. Chronic Media Worlds: Social Media and the Problem of Pain Communication on Tumblr. Soc Media + Soc. 2016;January-March 2016:1–11.

[3] Newton BJ, Southall JL, Raphael JH, et al. A Narrative Review of the Impact of Disbelief in Chronic Pain. Pain Manag Nurs. 2013;14(3):161–171.

[4] Kleinman A. The Illness Narratives. Suffering, Healing & the Human Condition. Durham and London: Duke University Press; 1988.

[5] Steinkopf L. An Evolutionary Perspective on Pain Communication. Evol Psychol. 2016;April-June 2016:1–7.

[6] Hyvärinen M. Analyzing Narrative Genres. In: De Fina A, Georgakopoulou A, editors. The Handbook of Narrative Analysis. Oxford: Wiley Blackwell; 2015. p. 178–193.

[7] Williams G. The genesis of chronic illness: narrative re-construction. Sociol of Health and Illn. 1984;6(2):175–200.

[8] Goffman E. The Presentation of Self in Everyday Life. New York (NY): Doubleday Anchor Books; 1959.

[9] Brashers DE. Communication and Uncertainty Management. J of Commun. 2001;51(3):477–497.

[10] Ressler PK, Bradshaw YS, Gualtieri L, et al. Communicating the Experience of Chronic Pain and Illness Through Blogging. J of Med Internet Res. 2012;14(5):e143.

[11] Breivik H, Borchgrevink PC, Allen SM, et al. Assessment of pain. Br J of Anaesth. 2008;101(1):17–24.

[12] Hydén LC. Illness and narrative. Sociol of Health and Illn. 1997;19(1):48–69.

[13] Østbye T, Yarnall KSH, Krause KM, et al. Is There Time for Management of Patients With Chornic Diseases in Primary Care? Ann of Fam Med. 2005;3(3):209–214.

[14] Hess A. The Social Media Cure. Slate [Internet]. 2016 Mar 4 [cited 2017 Dec 5];Technology:[about 13 paragraphs]. Available from: http://www.slate.com/articles/technology/users/2016/03/how_spoonies_people_with_chronic_illnesses_use_memes_selfies_and_emojis.html

[15] Salzmann-Erikson M, Hiçdurmaz D. Use of Social Media Among Individuals Who Suffer From Post-Traumatic Stress: A Qualitative Analysis of Narratives. Qual Health Res. 2017;27(2):285–294.

[16] Hadjistavropoulos T, Craig KD. A theoretical framework for understanding self-report and observational measures of pain: a communications model. Behav Res and Ther. 2002;40(5):551–570.

[17] Keim-Malpass JK, Stegenga B, Loudin C, et al. 'It's Back! My Remission Is Over': Online Communication of Disease Progression Among Adolescents With Cancer. J of Pediatr Oncol Nurs. 2016;33(3):209–217.

[18] Frank AW. The Wounded Storyteller: Body, Illness, and Ethics. Chicago (IL): The University of Chicago Press; 1995.

[19] Gonzalez-Polledo E, Tarr J. The thing about pain: The remaking of illness narratives in chronic pain expressions on social media. New Media & Soc. 2016;18(8):1455–1472.

[20] Brosseau L, Wells G, Brooks-Lineker S, et al. Internet-Based Implementation of Non-Pharmacological Interventions of the

"People Getting a Grip on Arthritis" Educational Program: An International Online Knowledge Translation Randomized Controlled Trial Design Protocol. JMIR Res Protoc. 2015;4(1):e19.

[21] Sendra A, Farré J. Institutional pain communication via Twitter by Spanish and US pain societies: Analysis of levels of use and engagement. Catalan J of Commun and Cult Stud. 2017;9(1):3–23.

[22] Carlyle KE, Guidry JPD, Williams K, et al. Suicide conversations on Instagram: contagion or caring? J of Commun in Healthc. 2018; 11(1):12–18.

[23] Tarr J, Cornish F, Gonzalez-Polledo E. Beyond the binaries: reshaping pain communication through arts workshops. Sociol of Health and Illn. 2018;40(3):577–592.

[24] Pittman M, Reich B. Social media and loneliness: Why an Instagram picture may be worth more than a thousand Twitter words. Comput in Hum Behav. 2016;62(September 2016):155–167.

[25] Guynn J. Bye Facebook, hello Instagram: Users make beeline for Facebook-owned social network. USA Today [Internet]. 2018 Mar 23 [cited 2018 June 28]; Tech. Available from: https://eu.usatoday.com/story/tech/news/2018/03/22/byefacebook-hello-instagram-users-make-beeline-facebook-owned-socialnetwork/433361002/

[26] Plummer K. Telling Sexual Stories. Power, Change and Social Worlds. London and New York (NY): Routledge; 1995.

[27] Ong BN, Hooper H, Dunn K, et al. Establishing self and meaning in low back pain narratives. The Sociol Rev. 2004;52(4):532–549.

[28] Carter B. Pain narratives and narrative practitioners: a way of working 'in-relation' with children experiencing pain. J of Nurs Manag. 2004; 12(3):210–216.

[29] Gruzd A. Netlytic: Software for Automated Text and Social Network Analysis [Software]. Available from: https://netlytic.org/

[30] Palinkas LA, Horwitz SM, Green CA, et al. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm and Policy in Ment Health Serv Res. 2015;42(5):533–544.

[31] Rose G. Visual Methodologies: An introduction to the interpretation of visual materials. London: SAGE Publications; 2001.

[32] Johnson MI, Hudson M. Generalizing, deleting and distorting information about the experience and communication of chronic pain. Pain Manag. 2016;6(5):411–414.

[33] Sontag S. Illness as Metaphor. New York (NY): Farrar, Straus & Giroux; 1978.

[34] Sontag S. AIDS and Its Metaphors. New York (NY): Farrar, Straus & Giroux; 1989.

[35] Wright KB, Sparks L, O'Hair HD. Health Communication in the 21st Century. Oxford: Blackwell Publishing; 2008.

[36] Chou WS, Hunt Y, Folkers A, et al. Cancer Survivorship in the Age of YouTube and Social Media: A Narrative Analysis. J of Med Internet Res. 2011;13(1):e7.

[37] Morris DB. Narrative and Pain: Towards an Integrative Model. In: Moore RJ, editor. Handbook of Pain and Palliative Care. New York (NY): Springer; 2013. p. 733–751.

[38] Du Pré A. Communicating about health: Current issues and perspectives. New York (NY): Oxford University Press; 2014.

[39] Pedersen AR. The role of patient narratives in healthcare innovation: supporting translation and meaning making. J of Health Organ and Manag. 2016;30(2):244–257.

[40] National Health Service (NHS). Fibromyalgia. NHS choices [Internet]. 2016 Mar 1 [cited 2017 Oct 2];Conditions:[about 5 screens]. Available from: https://www.nhs.uk/Conditions/Fibromyalgia/Pages/Diagnosis.aspx

[41] Prentice A. Endometriosis. Br Med J. 2001;323:93–95.

[42] Hester JL. Living With Invisible Illness. The Atlantic [Internet] 2015 Jul 17 [cited 2017 Dec 5];Health:[about 25 paragraphs]. Available from: https://www.theatlantic.com/health/archive/2015/07/invisible-illness-chronicdisease-fibromyalgia/398393/

[43] National Health Service (NHS). Endometriosis. NHS choices [Internet]. 2015 Sep 9 [cited 2017 Oct 2];Conditions:[about 5 screens]. Available from: https://www.nhs.uk/Conditions/Endometriosis/Pages/Introduction.aspx

[44] Mol A. The body multiple: ontology in medical practice. Durham and London: Duke University Press; 2002.

[45] WebMD. How Pain Affects Men and Women Differently. Pain Management Health Center [Internet]. N.D. [cited 2018 Jul 9];References:[about 2 paragraphs]. Available from: https://www.webmd.com/painmanagement/chronic-pain-conditions#1

[46] Noel M, Beals-Erickson SE, Law EF, et al. Characterizing the Pain Narratives of Parents of Youth With Chronic Pain. The Clin J of Pain. 2016;32(10):849–858.

[47] Sharf BF. Communicating Health through Narratives. In: Yamasaki J, Geist-Martin P, Sharf BF, editors. Storied Health and Illness: Communicating Personal, Cultural, and Political Complexities. Long Grove, Illinois (IL): Waveland Press; 2016. p. 29–53.

[48] Han J, Wiley J. Digital Illness Narratives: A New Form of Health Communication. Trans of the Int Conf on Health Inf Technol Adv 2013. 2013;2(1):47–52.

[49] Wang R, Jinyoung K, Xiao A, et al. Networked narratives on Humans of New York: A content analysis of social media engagement on Facebook. Comput in Hum Behav. 2017;66(January 2017):149–153.

[50] Thackeray R, Brad L., Smith AK, et al. Adoption and use of social media among public health departments. BMC Pub Health. 2012;12:242.

[51] Smith A, Anderson M. Social Media Use in 2018. Pew Research Center [Internet]. 2018 Mar 1 [cited 2018 Jul 10];Internet and Technology:[about 22 paragraphs]. Available from: http://www.pewinternet.org/2018/03/01/social-media-use-in-2018/

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[i] Platforms like Facebook or Twitter allow users to share posts without visuals, a feature that Instagram does not have.

[ii] Netlytic is a social media analysis software created by The Social Media Lab (Ryerson University) for the researcher community that, unlike other similar applications, recovers data from Instagram and YouTube as well as Facebook and Twitter.

[iii] The criterion-i strategy is a purposeful sampling technique that identifies and selects “information-rich cases” [30, p.534]: “[p]articipants who meet or exceed a specific criterion or criteria possess intimate (…) knowledge of the phenomenon of interest by virtue of their experience” [30, p.539].

[iv] The sample had a confidence level of 95% (with a confidence interval of 5.12).

[v] For Frank [18], chaos narratives are not narratives in a strict sense, because “these stories cannot literally be told but can only be lived” [18, p.98]. For this author, the posts would reflect the voice of chaos, as an element that allows the reconstruction of the story of these patients [18].

[vi] Of the posts included in the final sample, 10.3% (n=36) did not name the illness of the profile owner.

[vii] In general, these visual representations (photographs, etc.) are coherent with the text of the post accompanying them.

[viii] As Hess [13] explains, the term “spoonie” comes from “spoon theory”. According to this theory, chronic pain sufferers have a limited number of spoons — which represent units of energy — to get through the day. When they have used up all the spoons, patients no longer have energy until the next day. The term “spoonie” has become very popular among people with chronic pain, who use it to denominate themselves.

4.5 Study IV

Seeking, sharing and co-creating: a systematic review of the relation between social support theory, social media use and chronic diseases

Seeking, sharing and co-creating: a systematic review of the relation between social support theory, social media use and chronic diseases

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Conflict of interest

The authors declare that there is no conflict of interest.

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ABSTRACT

The use of social media is increasing in the treatment and management of health. Patients with chronic diseases are especially interested in using these technologies to look for support, but organizations are lagging behind. The aim of this study is to explore the implications of applying social support theory to social media use in the field of chronic diseases. A systematic review was conducted in the Web of Science Core Collection database. Our analysis retrieved 10 registers on initiatives around social support theory, social media, and chronic diseases. Despite the paucity of initiatives from this perspective, the studies included in this review offer some recommendations on how health-related organizations can improve patient-physician communication. Our findings suggest that social media can provide social support regularly, but institutions need to create safe environments addressed to specific diseases where physicians also take part in the community of the site. As patients have been in social media without physicians' support for many years now, finding new ways of reducing the communicative gap between these two stakeholders is crucial. This review suggests that the application of social support theory could be one of the solutions, especially regarding chronic pain patients.

KEYWORDS

social support, chronic disease, social media, health communication, patients, physicians

INTRODUCTION

The traditional healthcare delivery model is close to being exhausted. Since the 2.0 disruption, patients are increasingly using m-health apps, wearables, social media platforms, and similar, to manage their health conditions. Only in the US, 7 out of 10 consumers want to use technology to improve their health care, according to a survey conducted in 2016 (Korenda *et al*, 2016). Moreover, a worldwide report from 2014 says that 90% of patients look for health information online (PatientView, 2015). Against this background, health institutions are under pressure to find new ways to engage and communicate with their patients in these environments (Sendra and Farré, 2017).

One of the tools that could be the next revolution in the treatment and self-management of healthcare is social media (Laestadius, 2017). Apart from being powerful platforms to enhance patient-physician communication (McKenna, 2017), patients are actively using social media due to the diverse types of support they receive in these spaces (Deng and Liu, 2017). In their study about online support groups, Coulson and Shaw (2013, p. 1698) argue that these spaces work as *communal brains* where patients can "access a wealth of both factual and experiential information, advice and support". With the creation of these ties, patients experience a *buffering effect* (Heaney and Israel, 2002).

Even though there are other theoretical perspectives (Wright, 2016a) that are used to study online communities (like the Optimal Matching Model (coincidence between provider and receiver), the Social Comparison Theory (experiences are normalized when comparing with others), or the Social Information Processing Theory (the support provided through online tools is seen as positive)), the Buffering Effect Model is the one that fits best the reality of social media. In face-to-face interactions, this model has proved that participating in the group reduces the stress of the patients (Wright, 2016a). At the same time, in online environments, the buffering effect permits the network to grow (along with greater participation in the community) (Wright, 2016a). Applied to platforms like social media, this model permits the combination of both realities (benefits of face-to-face and online interactions).

There is as well another theory that can be applied to the context of social media, called the Strength of Weak Ties Theory (Wright *et al*, 2010; Wright, 2016a). According to this perspective, the reach of the support depends on the structure of the community (Wright, 2016a). This theory could be used by healthcare organizations to analyse if these patients' interactions within these platforms are really beneficial or not (Frohlich, 2014). The difference between the two models is that the buffering effect is more health-oriented, while the Strength of Weak Ties Theory is "more communication process-oriented" (Wright, 2016a, p. 76). Nevertheless, even if institutions use one or the other theoretical perspective, online "groups/communities can offer a number of advantages […] in terms of social support" (Wright, 2016b, p. 2).

The practice of looking for this kind of assistance is quite common between patients with chronic diseases (Frohlich, 2014; Merolli *et al*, 2013a; Metha and Atreja, 2015), especially among those affected by chronic pain (Keim-Malpass *et al*, 2016; Ressler *et al*, 2012). Since illnesses like fibromyalgia are very difficult to diagnose (Hester, 2015), patients turn to social media to build "a sense of community among people with similar health issues" (Deng and Liu, 2017, p. 100) and share stories with peers (Hess, 2016). As Alhaboby *et al* (2017, Social Identity in Online Support Groups, para. 1) argue, "having an 'invisible disability' … seemed to be influencing participants' attitudes towards sharing their experiences". However, the fact that social relationships provide support is not new. Back in 1980, Kahn and Antonucci formulated the convoy model, where "the individual is seen in a life course perspective as travelling through life surrounded by members of his/her cohort who share experiences and life histories and who provide support to one another reciprocally over time" (Kahn and Antonucci, cited in Berkman *et al*, 2000, p. 846). The difference is that now these practices are happening in social media.

Although having a beneficial impact (Merolli *et al*, 2013b), these online connections are rarely discussed in terms of social support. According to this health communication theory that describes "the functional content of relationships" (House, cited in Heaney and Israel, 2002, p. 186), social support can be classified in four types: emotional (providing empathy, affection… and similar), instrumental (offer services), informational (giving information) and appraisal support (supplying practical resources for self-evaluation) (Deng and Liu, 2017; Heaney and Israel, 2002). In a study published in 2010, emotional and appraisal support "were validated in the context of social media websites" (Cha, cited in Deng and Liu, 2017, p. 100).

At the same time, support happens within networks. With social media, now there are spaces where these connections can take place without the necessity of face-to-face interactions. However, the origin of these online platforms lies on social networks. According to Israel, networks have three dimensions: structural (number of connections), interactional (how these connections take place, based on frequency and reciprocity), and functional (which are the roles of the members) (Israel, 1985). All these features, which define social relationships (Israel, 1985), are also taking place in social media. Though networks work correctly through the combination of the three features (Israel, 1985), the interactional dimension is a crucial characteristic of social networks –especially in online environments like social media–: if the users of the network do not interact, the provision of support through these platforms cannot take place.

In this sense, while patients are actively communicating with each other on these platforms; health organizations and their professionals are falling behind due to strict regulations (Harris *et al*, 2013), lack of time, or simply because they do not know how to effectively use these tools (Sendra and Farré, 2017). As Roland (2018, p. 151) points out, “despite relatively wide availability of resources in relation to how to use social media to disseminate information, in particular Twitter and Facebook, many researchers felt poorly informed and equipped to do this”. Moreover, another study found that "online groups' members were cautious in dealing with 'outsiders', being academics or healthcare professionals" (Alhaboby *et al*, 2017, Social Identity in Online Support Groups, para. 3). In other words, those who participate in social media for health reasons trust peers more than 'superior' figures, like doctors or nurses. This type of behaviour increases the communication gap between patients and physicians.

Although "moderating an online forum can enable the moderator and users to proactively manage their condition, to deal more effectively with health care professionals and to better access health care services available to them" (Coulson and Shaw, 2013, p. 1699); health-related institutions cannot fall behind since the use of social media involves certain risks, like lack of reliability, privacy concerns or information overload (Roland, 2018). It is the responsibility of these organisations to address those potential risks to that the use of these technologies is not harmful to patients. In the end, participating in these communities helps people "reinterpret events or problems in a more positive and constructive light" (Thoits, cited in Heaney and Israel, 2002, p. 189). Social support theory also discusses the possibility of sharing this moderator role: "a combination of formal and informal helpers may be the most effective in situations in which both informational and emotional support are needed" (Heaney and Israel, 2002, p. 195). What is clear is that health-related institutions need to learn how they can use digital technologies to improve the traditional healthcare delivery system.

Aims

At a time when health 2.0 is reaching a defining moment, Wright (2016b, p. 4) suggests that "more meta-analyses and meta-analytic reviews will be needed to assess the impact of social networks/relationships on health across similar studies". In this sense, previous reviews have explored the relationship between social media and health from different perspectives. For example, Moorhead *et al* (2013) analysed the uses of social media for health communication. Other reviews explored how social media can improve chronic disease management (Allen *et al*, 2016; Merolli *et al*, 2013a; Patel *et al*, 2015). On the other hand, Vianna and Barbosa

(2017) investigated how computing can aid social support in non-communicative diseases. Another study even examined how Twitter content analysis can be improved for health researchers (Hamad *et al*, 2016). However, none of these reviews explored the relation between social support theory, social media and chronic diseases from a communicative perspective. For this reason, this study explores the implications of applying the social support theory to social media use in the field of chronic diseases.

By conducting a systematic review, our research has a twofold objective: (1) to determine how many initiatives exist in social media that have been applying social support theory in the field of chronic disease; and (2) to provide a list of recommendations about how health institutions can improve the communication with their patients in social media relating to advances in health communication theory. Due to the innovative approach, it is assumed that there are few initiatives that are applying social support theory in the field of chronic diseases.

METHODS

The PRISMA recommendations for improving the publication of systematic reviews and meta-analysis were followed (Urrútia and Bonfill, 2010). The review included all the studies that met the following inclusion criteria: (1) studies related to chronic diseases, (2) articles related to social media, (3) peer-reviewed articles published in English between 2004 and December 2017, (4) studies related to the social support theory, and (5) studies related to the object of study.

Data Search

The search was conducted in the Web of Science Core Collection database (see Table 1).

For this search, the following keywords were used: **(chronic (disease OR illness) AND social support) AND (social media)**. We have used the keyword *social media* instead of *social network* to prevent confusion between the two terms, since the expression *social network* "refers to the web of social relationships that surround individuals" (Heaney and Israel, 2002, p. 8). In contrast, *social media* "are the various platforms, generally Internet based, that enable communication among users using a unique frame of reference" (Roland, 2018, p. 149). After conducting the search under these keywords, we obtained 94 results. An additional 7 studies were added after picking them through reference lists, leaving a final sample of 101 papers to be analysed.

Table 1. Databases used for this review.

Web of Science Core Collection: Citation Index
Science Citation Index Expanded (SCI-EXPANDED)
Social Sciences Citation Index (SSCI)
Arts & Humanities Citation Index (A&HCI)
Conference Proceedings Citation Index-Science (CPCI-S)
Conference Proceedings Citation Index-Social Sciences & Humanities (CPCI-SSH)
Book Citation Index-Science (BKCI-S)
Book Citation Index-Social Sciences & Humanities (BKCI-SSH)
Emerging Sources Citation Index (ESCI)

Study Selection

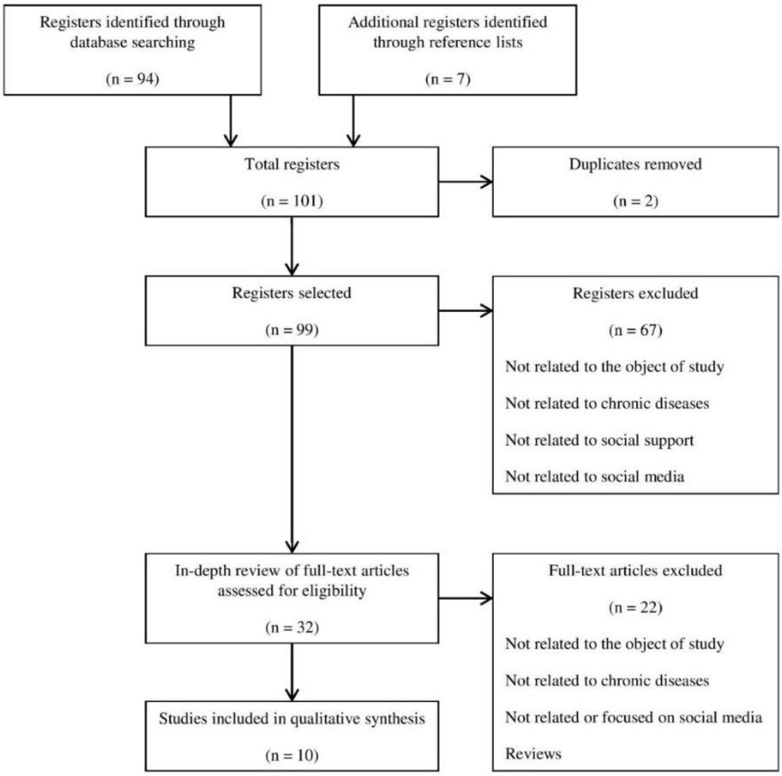
As Figure 1 shows, the first step was removing the duplicates (2), reducing to 99 the studies selected for the analysis. Then, these registers were individually examined (by reading the abstracts) to determine if they met the inclusion criteria defined for this study. In this second phase, 67 papers were excluded for various reasons (not related to the object of study, not related to chronic diseases, not related to social support, or not related to social media). After concluding this second step, 32 studies were selected for a full-text in-depth review. Again, in the third phase, 22 full-text articles were excluded for different causes (not related to the object of study, not related to chronic diseases, not related or focused on social media, or for being reviews).

Once the analysis was completed, only 10 registers were included in the qualitative synthesis of the study (see Figure 1).

RESULTS

As suggested, it seems that there is a lack of initiatives that are applying the social support theory to social media use in the field of chronic diseases. Table 2 assembles the 10 papers collected in the qualitative synthesis, all of them related to social media in different ways. Later, in the discussion part, we are going to examine common topics between these studies, and explore how healthcare can be improved considering the advances of social support theory and the use of social media platforms.

Figure 1. Flowchart of the different phases of the systematic review.



Firstly, out of the 10 papers included in the qualitative synthesis, we can see a variety of countries where these studies were conducted: 3 in the US, 2 in Israel, 1 in Canada, 1 in Australia, 1 in Sweden, 1 in Italy, and 1 in South Korea. This fact also leads to a diversity of languages of the initiatives developed in the studies: most of the interventions were implemented in English (n=6); but also in Hebrew (n=2), Italian (n=1) and Swedish (n=1).

Concerning the social media platform used, the results were the following: 4 of the 10 studies are using existing platforms (like Facebook or Twitter) for their analysis (n=4); another 4 have created their specific social media platform according to the chronic disease they are studying (n=4); 1 paper explores the implementation of a chronic pain management workshop; and, finally, the remaining study discusses web 2.0 tools more generally. Moreover, most of the initiatives were focused on the treatment of chronic diseases in general (n=6); except for 2 studies dedicated specifically to diabetes (n=2), 1 to rheumatoid arthritis (n=1), and 1 to multiple sclerosis (n=1).

The studies also present various methodological approaches: of the 10 papers included in the qualitative synthesis, 4 opt for quantitative methods (n=4), 3 for qualitative techniques (n=3), 2 for mixed-methods procedures (n=2), and the last study opts for a theoretical approach (n=1). At the same time, most of the studies had participants (chronic disease patients) who were directly affected by the illnesses analysed in the studies (n=7); apart from 2 papers that

Table 2. Papers included in the qualitative synthesis of the study.

Author/s, year	Social media used	Chronic disease or illness analysed in the study	Aim of the study	Patients/ users reached	Methodology	Results	Country, language
Becker (2013)[33]	Better Choices, Better Health (6-week online chronic pain management workshop)	Multiple (epilepsy, high blood pressure, osteoarthritis, depression, sleep apnea, hypertension, type 2 diabetes, MS, chronic back pain, chronic sinusitis, fibromyalgia, rheumatoid arthritis)	Examination of the discursive practices of chronic pain sufferers on online environments	18 participants 2 facilitators	Qualitative (discourse analysis)	The workshop provides support (cyberhug), legitimize the pain of the sufferers and offer clues to improve patient-provider communication	US (English)
Brosseau et al. (2015)[34]	Facebook (as a part of the PGrip-RA, an online program for patients with rheumatoid arthritis)	Rheumatoid arthritis (RA)	Examination of the effects of the implementation of an online program for patients with RA, with help from healthcare professionals and electronic brochures	396 people with RA across Australia and Canada (prediction)	Quantitative (Randomized Controlled Trial – RCT)	Facebook and other online tools have potential to provide education, information and self-management programs for people with arthritis at an economic cost	Canada (English)
Fatima et al. (2015)[35]	Twitter (as a part of a monitoring that also includes data from trajectories and email analysis to develop a Social Media and Interaction Engine (SMIE))	Chronic diseases in general	Using the data from different patient's social interactions to improve healthcare support system through a Smart Clinical Decision Support System (Smart CDSS)	6000 patients' tweets	Mixed methods	The combination of the SMIE analysis with Smart CDSS systems helps providers into better decision making for their patients	South Korea (English)

(continuation of Table 2)

Author/s, year	Social media used	Chronic disease or illness analysed in the study	Aim of the study	Patients/ users reached	Methodology	Results	Country, language
Grosberg et al. (2016)[36]	Camoni	Multiple (diabetes mellitus, pain, depression, hypertension)	Measure the level of patient activation (PA) of individuals who participate in a health-based social media	277 participants	Quantitative (Cross-Sectional Survey)	Camoni increases PA of individuals who use this platform to discuss and increase knowledge about their diseases	Israel (Hebrew)
Lavorgna et al. (2017)[37]	SMsocial network .com	Multiple sclerosis (MS)	Determine the impact of using the SMsocialnetwork.com on MS coping and social interaction between people with this disease	130 users	Quantitative (Web-Based Survey)	Users perceive the SMsocialnetwork.com as a useful tool to support MS coping and social interaction between people with this disease	Italy (Italian)
Magnezi et al. (2014)[38]	Camoni	Multiple (diabetes, heart disease, spinal injury, kidney disease, depression/anxiety)	Examination of the effects and benefits of the participation in a health-based social media	296 participants	Quantitative (Cross-Sectional Survey)	Health-based social media platforms like Camoni are helpful for individuals with lower levels of patient activation	Israel (Hebrew)
Merolli et al. (2015)[39]	Facebook, YouTube and chronic pain blogs	Multiple (fibromyalgia, osteoarthritis, posttraumatic stress, temporomandibular joint syndrome, sciatica, low back pain)	Determine which research design aspects are fundamental to achieve the success of implementing a larger-scale study of social media in chronic pain management	17 patients	Mixed methods (semi-structured interviews and questionnaires)	Larger-scale studies of social media in chronic pain management may not be appropriate for all chronic pain sufferers. Also, patients should be more empowered about the social media resources they choose for information about their pain	Australia (English)

(continuation of Table 2)

Author/s, year	**Social media used**	**Chronic disease or illness analysed in the study**	**Aim of the study**	**Patients/ users reached**	**Methodology**	**Results**	**Country, language**
Milani and Lavie (2015)[40]	Web 2.0 tools	Chronic diseases in general	Conceptualizing the development of a new model where web 2.0 technologies are the core of the change of the healthcare delivery system	-	Theoretical article	The healthcare system needs to develop a new care delivery model to manage the increasing problem of chronic diseases	US (English)
Nordfelt et al. (2010)[41]	Diabit	Type 1 diabetes	Examination of patients' and parents' attitude to a diabetes-based social media created specifically to support the management of the disease	24 participants	Qualitative (content analysis)	Diabit is a good resource to provide information and support management to parents and patients with type 1 diabetes	Sweden (Swedish)
Rus and Cameron (2016)[42]	Facebook	Diabetes	Determine which are the type of messages that increase user engagement of organizations that provide diabetes information and support through Facebook	500 posts of 10 diabetes-related pages	Qualitative (content analysis)	Messages about negative affect, social support, positive identity, crowdsourcing, and external links generates more user engagement. Also, posts with images generates more response from the users than messages without them	US (English)

only analysed social media data (n=2), and the theoretical study – that didn't have participants (n=1).

Finally, according to the results, we can classify the studies into 3 groups: most of the papers discuss (a) the implications of using social media platforms in healthcare delivery or treatment (Becker, 2013; Brosseau *et al*, 2015; Fatima *et al*, 2015; Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014; Nordfelt *et al*, 2010; Rus and Cameron, 2016); (b) but there is also a study based on design improvement of large-scale studies (Merolli *et al*, 2015); (c) and another paper that discusses healthcare delivery models (Milani and Lavie, 2015).

DISCUSSION

As mentioned earlier, there are indeed few studies analysing the application of social support theory to social media use in the field of chronic diseases. As Roland (2018, p. 14) points out, "the specific role of social media in health policy has been relatively poorly explored". Nevertheless, even with this lack of literature, the studies included in the qualitative synthesis present some interesting results that can be used to improve the communication between patients and physicians. In the end, within health-related organizations "there is a need for clear guidelines on how healthcare professionals make use of social media to support their patients" (McKenna, 2017, p. 470).

At the same time, of the different types of social support described by Heaney and Israel, we need to bear in mind that instrumental support can't take place in social media since it "involves the provision of tangible aid and services that directly assist a person in need" (Heaney and Israel, 2002, p. 186). Since these platforms function exclusively online –and the process of communication takes place without the need of physical presence, instrumental support cannot be applied to these technologies. Therefore, we can only consider emotional, instrumental and appraisal support in our analysis. As Table 3 shows, the papers included in the analysis suggest that social media technologies involved in the studies are valid platforms to promote these three types of social support (see Table 3).

Table 3. Types of social support implemented in the studies.

Author	Social support implemented
Becker (2013)[33]	emotional and informational support
Brosseau et al. (2015)[34]	emotional, informational and appraisal support
Fatima et al. (2015)[35]	informational and appraisal support
Grosberg et al. (2016)[36]	emotional, informational and appraisal support
Lavorgna et al. (2017)[37]	emotional, informational and appraisal support
Magnezi et al. (2014)[38]	emotional, informational and appraisal support
Merolli et al. (2015)[39]	informational support
Milani and Lavie (2015)[40]	emotional, informational and appraisal support
Nordfelt et al. (2010)[41]	emotional and informational support
Rus and Cameron (2016)[42]	informational support

First, Heaney and Israel (2002, p. 186) define informational support as the "provision of advice, suggestions, and information that a person can use to address problems". In the case of the studies analysed, whether they are interventions that are using different social media platforms where patients can find information about their chronic disease (Brosseau *et al*, 2015; Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014; Merolli *et al*, 2015; Nordfelt *et al*, 2010; Rus and Cameron, 2016), or initiatives that are analysing social media data to improve health services provided through an app (Fatima *et al*, 2015), the presence of this type of support is always there. As social media are applications that "are designed to enable users to create, interact, collaborate and share in the process of creating as well as consuming content" (Obar and Wildman, 2015, p. 746), providing content is within the nature of these technologies. Moreover, this co-creation of content in these platforms allows to "generate more available health information" online (Moorhead *et al*, 2013, p. e85).

This is important since "those who access health information over the Internet are more likely to have higher PAM [Patient Activation Measure]" (Grosberg *et al*, 2016, p. 212), especially in chronic disease patients. On the one hand, sites like Camoni offer "medical advice, including blogs, forums, support groups, internal mail, chats, and an opportunity to consult with experts" (Magnezi *et al*, 2014, p. e12; Grosberg *et al*, 2016). Other portals, like Diabit (Nordfelt *et al*, 2010), have different types of content (like text pages or videos) created by health professionals for the patients to access to it. To find these kinds of sources on the portals generates security to users, as they can find "correct, reliable information provided by local practitioners" all in one place (Nordfelt *et al*, 2010, p. e17). But, as Fatima *et al* (2015) argue, informational support also can be improved by analysing social media data generated by patients to provide better and more specific information to them.

Secondly, the social media tools present in the papers analysed are also providing emotional support (Becker, 2013; Brosseau *et al*, 2015; Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014; Nordfelt *et al*, 2010). This kind of support "involves the provision of empathy, love, trust, and caring" (Heaney and Israel, 2002, p. 186). In the studies reviewed, emotional support is manifested in two ways. On the one hand, health professionals take part in the online community (Brosseau *et al*, 2015; Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014). Their role is based on answering the doubts of these chronic patients in real-time, like in the case of the SMsocialnetwork.com: on this platform, there is a "constant online presence of neurologists and psychologists from the medical team to oversee and participate on the public wall" (Lavorgna *et al*, 2017, p. e10). But emotional support also occurs among the patients themselves, when sharing their stories in these communities and feeling identified with other peers with exactly the same problems (Becker, 2013; Nordfelt *et al*, 2010). It's what Becker (2013) calls *cyberhug*. This duality responds to the necessity of finding professional help, but at the same time shows distrust to recommendations that come from people who do not suffer from chronic diseases. For these patients, advice from peers seems to be more authentic (Becker, 2013). According to the logic of the Strength of Weak Ties Theory (Wright *et al*, 2010; Wright, 2016a), this authenticity can take place also in social media even if the connections between the network are not that close. On these platforms, natural helpers –either formal or informal– are seen as reliable sources because they "are able to offer specialized information about a problem" (Wright, 2016a, p. 75).

To a lesser extent, appraisal support is also provided through these technologies (Brosseau *et al*, 2015; Fatima *et al*, 2015; Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014). As defined by Heaney and Israel (2002, p. 186), this type of support "involves the provision of information that is useful for self-evaluation purposes". In portals like SMsocialnetwork.com, users receive "innovative, effective, and practical solutions regarding MS-related issues and management" (Lavorgna *et al*, 2017, p. e10). At the same time, in sites like Camoni where each community is run by a health professional, users have at their disposal "practical advice on how to maintain one's health and cope with the disease" (Magnezi *et al*, 2014, p. e12).

The provision of appraisal support through social media is crucial, since chronic diseases involve continuous problems –like in the case of pain (Kleinman, 1988)–, disabilities, reduced mobilities… among others. Having online platforms where professionals can offer patients self-management solutions right away increases automatically the efficacy of the healthcare system: on the one hand, professionals gain time for other matters (like taking care of more appointments); and, on the other hand, organizations can reduce costs (because the user can receive reliable recommendations from health personnel without leaving their homes). As Milani and Lavie (2015, p. 341) discuss in their study about care models, it is time now for healthcare to "reengineer its care delivery model to manage the chief medical crisis of the 21st century, chronic disease".

The review of the papers also hints at some common patterns between the initiatives analysed. In the first place, the studies suggest that social media can provide social support regularly, making patients more motivated and engaged (Grosberg *et al*, 2016; Magnezi *et al*, 2014; Merolli *et al*, 2015). By engaging more health professionals into the use of these technologies (Milani and Lavie, 2015), organisations have the opportunity to address the Internet problem of misinformation (Ahmad *et al*, 2006). Likewise, they need to create platforms that acknowledge "patient preferences for resources that adequately address disease-specific needs" (Merolli *et al*, 2015, p. e101), like the Diabit portal (Nordfelt *et al*, 2010). If health-related organizations only use these tools to provide informational support without taking part in the conversations with their users (Sendra and Farré, 2017), the communicative gap between these two stakeholders will get bigger, and patients will have even more options for an extremely independent self-management of care without the necessity of involving health professionals. As Coulson and Shaw (2013, p. 1699) argue, receiving support through online communities could lead patients to an "unwillingness to engage with traditional forms of healthcare".

Secondly, the provision of social support seems to work better when offered from specific social media or portals addressed to specific groups –like in the cases of Camoni, Diabit and SMsocialnetwork.com (Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014; Nordfelt *et al*, 2010)–, rather than using existing platforms and integrating them as a part of an intervention program (Brosseau *et al*, 2015; Merolli *et al*, 2015; Rus and Cameron, 2016). By using a unique platform, all the services organizations can provide are centralized in one place. Likewise, these online spaces act as a safe place for patients (Becker, 2013; Nordfelt *et al*, 2010). Furthermore, most of the studies in our qualitative synthesis came to the conclusion that, in social media, patients look for information and groups that are specifically addressed to their illness (Becker, 2013; Grosberg *et al*, 2016; Magnezi *et al*, 2014; Nordfelt *et al*, 2010).

In the end, “each patient has individualized needs” (Merolli *et al*, 2015, p. e101). In the case of the SMsocialnetwork.com, the researchers came to the conclusion that using specific social media “may allow MS [multiple sclerosis] experts to reach a deeper comprehension of the needs of people with MS” (Lavorgna *et al*, 2017, p. e10). Whether the support is provided through specific health-related social media or through traditional platforms, organisations need to “careful design [...] social media-delivered health communication using specific features to promote specific types of engagement” (Rus and Cameron, 2016, p. 688).

In the third place, health professionals develop a key role on the social media initiatives discussed in the studies. Whether they act as moderators, or are actively participating in the conversations taking place on these platforms (Becker, 2013; Brosseau *et al*, 2015; Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014; Milani and Lavie, 2015; Nordfelt *et al*, 2010), they are the ones who should provide the social support their patients need to engage them in a better self-management of their health. Social support theory describes this figure as the natural helper (Heaney and Israel, 2002; Israel, 1985). According to these authors, "natural helpers are members of social networks to whom other network members naturally turn for advice, support, and other types of aid" (Israel, cited in Heaney and Israel, 2002, p. 198) who "are usually respected and trusted network members who are responsive to the needs of others" (Heaney and Israel, 2002, p. 198).

In the studies included in the qualitative synthesis, this role is developed with more or less intensity depending on the case. On the one hand, portals like SMsocialnetwork.com have a constant presence of health professionals on the platform to "oversee the public activities of the users, post relevant information about MS [multiple sclerosis], protect users from false rumors and fake news, [or] answer questions via private or public message" (Lavorgna *et al*, 2017, p. e10), among other functions. By contrast, with initiatives like the People Getting a Grip on Arthritis, these specialists are in the Facebook page only a few hours a week (Brosseau *et al*, 2015). Nevertheless, this natural helper role is not exclusively reserved to health professionals. Expert patients (that is to say, those who have been in social media for years) also can act as this figure (Becker, 2013; Nordfelt *et al*, 2010). Their roles, however, do not have to be excluding. As Heaney and Israel (2002, p. 195) argue, "a combination of formal and informal helpers may be most effective in situations in which both informational and emotional support are needed". One example of this is Patient Power (2005), a webpage addressed to cancer patients with multiple options according to the specific types of cancer. Involving health professionals by taking part in social media sites as natural helpers can also help in reducing the communicative gap between patients and physicians.

Lastly, another common point between the studies in our qualitative synthesis is the restricted access to these initiatives (Becker, 2013; Brosseau *et al*, 2015; Grosberg *et al*, 2016; Magnezi *et al*, 2015; Merolli *et al*, 2015; Nordfelt *et al*, 2010). In portals like Camoni, Diabit or SMsocialnetwork.com, participants require a register with user and password (Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014; Nordfelt *et al*, 2010). In other studies, participants were recruited via inclusion criteria (Brosseau *et al*, 2015; Merolli *et al*, 2015), which restricted opportunities for other patients to take part in the initiatives. For some patients, the result is looking for other resources that fulfil their expectations (Nordfelt *et al*, 2010). However, these kinds of barriers can help in addressing the problems of privacy and potential reputational harms (Roland, 2018). At a time where patients are "used to immediate results (instant messaging, instant meals, instant gratification, etc.) and […] prefer to obtain heath information online rather than wait for a physician consultation" (Magnezi *et al*, 2014, p. e12), organizations need to develop platforms that are accessible to all kinds of patients without forgetting to address these ethical concerns (like privacy or data storage). In the end, "understanding the consequences of using online resources is vital for keeping stride with evolving healthcare" (Rus and Cameron, 2016, p. 678).

CONCLUSIONS

As this review has shown, the application of social support theory to social media use in the field of chronic diseases still needs to come a long way. As we posited in our first objective, there is a paucity of studies working from this perspective. This review only found 10 of them (Becker, 2013; Brosseau *et al*, 2015; Fatima *et al*, 2015; Grosberg *et al*, 2016; Lavorgna *et al*, 2017; Magnezi *et al*, 2014; Merolli *et al*, 2015; Milani and Lavie, 2015; Nordfelt *et al*, 2010; Rus and Cameron, 2016). How can we explain this paucity? On the one hand, patients have been using social media in their own way without physicians taking part in their conversations; sometimes because they are not speaking the same language (Alhaboby *et al*, 2017; McKenna, 2017), at times because they do not have all the requirements to participate in these types of platforms. On the other hand, maybe because medical codes (starting with the Hippocratic Oath) still do not contemplate the use of social media and health 2.0 technologies for treatment and management of patients' health. However, this review suggests a solution to reduce the communicative gap between these two stakeholders. Before the creation of social media, Owen et al (2002, p. 510) started to hint at the possibility of using theories of social support in online support groups of "people with diseases viewed as stigmatizing". Now, with all the technological advancements that we have at our disposal, health-related institutions can create specific communities where patients and physicians can take part in the conversation simultaneously.

Apart from dealing with the inherent problems of the Internet (Roland, 2018), organizations have the opportunity of reshaping the healthcare delivery model by providing support to patients through these technologies; and, at the same time, creating a more economic and efficient health system (Milani and Lavie, 2015) where users can feel engaged again. Over the last years, patients (especially those with chronic diseases) have felt ejected from the health system for various reasons: lack of time in the appointments with their doctors to explain their problems more calmly, eternal waiting lists (for surgeries or visits to specialists), overmedication, etc. By not meeting their needs in the environment to which they habitually went, users started to look for other spaces or resources to feel heard and understood again. Now, health-related institutions have the opportunity to win back lost ground if they benefit from these tools to reconnect with their patients. In social media, organizations cannot act only as providers of information (Sendra and Farré, 2017). According to our second objective, from the results of this review we can extract a list of recommendations on how health institutions can address this communicative gap. In order to improve patient-physician communication, organizations should (1) use social media technologies to provide social support regularly; (2) create specific portals addressed to specific diseases; (3) include health professionals in the management of these sites as natural helpers; and (4) offer secure environments where patients can manage their health, and taking as few risks as possible.

In this sense, if chronic disease is the crisis of this century (Milani and Lavie, 2015), chronic pain is one of their major challenges. Only in Europe, 20 per cent of the population has chronic pain (150 million), and a 2 per cent of this group (15 million) has a pain that is difficult to live with (Eccleston *et al*, 2018). Moreover, pain is a growing health problem, because now populations live more and longer –and, in turn, they have more health problems (Milani and Lavie, 2015). Patients who suffer from this condition are one of the most active groups on social media (Gonzalez-Polledo, 2016), since their condition is often linked with isolation, distress and stigma (Newton *et al*, cited in Johnson and Hudson, 2016). In these spaces, they have found their community and space to share experiences with peers (Hess, 2016; Ressler *et al*, 2012). On the one hand, pain organizations do not engage with their communities online (Sendra and Farré, 2017). On the other hand, pain patients are in social media expressing their own narratives, and dealing with their identity and self-expression problems (Gonzalez-Polledo, 2016; Gonzalez-Polledo and Tarr, 2016). Particularly in this field, the gap between physicians and patients is quite large due to the aforementioned reasons. In the case of pain, the application of the principles of the social support theory (especially the introduction of natural helpers) could be one of the possible solutions according to the findings of this review.

Nevertheless, this study and the possible application of social support theory has its limitations. For now, researchers have only looked at the possible advantages of using social media for healthcare. One of them is that patients always benefit from taking part and participating on these platforms. On the one hand, there is the threats to privacy. From May 2018, the EU General Data Protection Regulation (GDPR) comes into force (EU General Data Protection Regulation Portal, n.d.). This will oblige organizations to have much stricter conditions for handling patient data. On the other hand, more studies are needed to analyse whether these online connections are really beneficial or not for patients. As Berkman *et al* (2000, p. 848) argue in their study about social networks, "not all ties are supportive and that there is variation in the type, frequency, intensity, and extent of support". In a similar way, Milani and Lavie (2015, p. 340) assert that "the fact that patients are embedded within social networks suggests that both good and bad behaviors could spread over a range of social ties". This is important since platforms like Facebook permits people "to reach out to others and mobilize support with relatively less effort, particularly in times of need" (Kim, 2014, p. 2213). Some studies have documented the positive impact of social media for pain patients (Merolli *et al*, 2013b), but what happens when the participation can lead to potential harm?

Are these practices between patients offering real solutions, or they are reinforcing the consequences of having an illness?

Moreover, it has to be taken into account that not everyone is in social media. As Merolli *et al* (2015, p. e101) claim, "until social media interventions can better address the needs of chronic pain patients who suffer from a lack of Internet access, poor literacy skills, poor Internet literacy, and language barriers, they will always be biased". At the same time, "one of the most challenging tasks of mobile social media providers and health policy makers is to encourage consumers to participate in self-health management" (Deng and Liu, 2017, p. 104). Without leaving aside these technological innovations, health-related organizations need to find a balance between online and offline management options. However, it is necessary to take into account the audiences (that is, patients) to change the system. In social media environments, these audiences –especially patients with chronic illnesses (Isika *et al*, 2015)– have gone on their own because institutions did not listen to them. According to Isika *et al* (2015), patients have appropriated these technologies for sharing knowledge. As "science is facing new challenges with the reality of social media's role in the spreading of knowledge based on personal anecdotes and fostering deceitful health messages" (Jervelund, 2018), health-related organizations need to work closely with their audiences if they want to address the existing communicative gap between patients and physicians.

In conclusion, since the irruption of 2.0 technologies, patients have always looking for a change in the way their health management is delivered. Although institutions are still in the early stages of reshaping the healthcare model, the results of this review suggest that the path for change is beginning to materialize. This study has shown that the implications of applying social support theory to social media use in the field of chronic diseases could be beneficial for improving patient-physician communication. Consequently, further research is needed to analyse the consequences of the application of social support theory to social media use in the long-run. With more or less intensity, patients and physicians are present on these online platforms. Now it is time for health organizations to use the advances in health communication theory to embrace the available technological revolution.

REFERENCES

Ahmad, F. *et al* (2006) Are physicians ready for patients with Internet-based health information? Journal of Medical Internet Research 8(3): e22.

Alhaboby, Z.A. *et al* (2017) Challenges facing online research: Experiences from research concerning cyber-victimisation of people with disabilities. Cyberpsychology: Journal of Psychosocial Research on Cyberspace 11(1): article 8.

Allen, C. *et al* (2016) Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers. Journal of Medical Internet Research 18(3): e61.

Becker, K.L. (2013) Cyberhugs: Creating a Voice for Chronic Pain Sufferers through Technology. Cyberpsychology, Behavior, and Social Networking 16(2): 123-126.

Berkman, L.F. *et al* (2000) From social integration to health: Durkheim in the new millennium. Social Science & Medicine 51(6): 843-857.

Brosseau, L. *et al* (2015) Internet-Based Implementation of Non-Pharmacological Interventions of the "People Getting a Grip on Arthritis" Educational Program: An International Online Knowledge Translation Randomized Trial Design Protocol. JMIR Research Protocols 4(1): e19.

Coulson, N.S. and Shaw R.L. (2013) Nurturing health-related online support groups. Exploring the experiences of patient moderators. Computers in Human Behavior 29(4): 1695-1701.

Deng, Z. and Liu, S. (2017) Understanding consumer health information-seeking behavior from the perspective of the risk perception attitude framework and social support in mobile social media websites. International Journal of Medical Informatics 105(September): 98-109.

Eccleston, C. *et al* (2018) Pain in Europe. In: C. Eccleston, C. Wells and B. Morlion (eds.) European Pain Management. Oxford: Oxford University Press, pp. 3-7.

EU General Data Protection Regulation Portal. (n.d.) GDPR Portal: Site Overview. Home Page of EU GDPR, https://www.eugdpr.org/eugdpr.org.html, accessed 20 March 2018.

Fatima, L. *et al* (2015) Smart CDSS: integration of Social Media and Interaction Engine (SMIE) in healthcare for chronic disease patients. Multimedia Tools and Applications 74(14): 5109-5129.

Frolich, D.O. (2014) The social support model for people with chronic health conditions: A proposal for future research. Social Theory & Health 12(2): 218-234.

Gonzalez-Polledo, E. (2016) Chronic media worlds: Social media and the problem of pain communication on Tumblr. Social Media + Society (January-March): 1-11.

Gonzalez-Polledo, E. and Tarr, J. (2016) The thing about pain: The remaking of illness narratives in chronic pain expressions on social media. New Media & Society 18(8): 1455-1472.

Grosberg, D. *et al* (2016) Frequent Surfing on Social Health Networks is Associated With Increased Knowledge and Patient Health Activation. Journal of Medical Internet Research 18(8): e212.

Hamad, E.O. *et al* (2016) Toward a Mixed-Methods Research Approach to Content Analysis in The Digital Age: The Combined Content-Analysis Model and its Applications to

Health Care Twitter Feeds. Journal of Medical Internet Research 18(3): e60.

Harris, J.K. *et al* (2013) Social media adoption in local health departments nationwide. American Journal of Public Health 103(9): 1700-1707.

Heaney, C.A. and Israel, B.A. (2002) Social networks and social support. In: K. Glanz, B.K. Rimer, and F.M. Lewis (eds.) Health Behavior and Health Education. Theory, Research and Practice. San Francisco: Wiley & Sons, pp. 185-209.

Hess, A. (2016) The Social Media Cure. Slate, 4 March, http://www.slate.com/articles/technology/users/2016/03/how_spoonies_people_with_chronic_illnesses_use_memes_selfies_and_emojis.html, accessed 10 March 2018.

Hester, J.L. (2015) Living With Invisible Illness. The Atlantic, 17 July, https://www.theatlantic.com/health/archive/2015/07/invisible-illness-chronic-disease-fibromyalgia/398393/, accessed 10 March 2018.

Isika, N.U. *et al* (2015) Appropriation of social media by patients with chronic illness to share knowledge. Proceedings of the Australasian Conference on Information Systems, https://minerva-access.unimelb.edu.au/handle/11343/58177, accessed 20 March 2018.

Israel, B.A. (1985) Social Networks and Social Support: Implications for Natural Helper and Community Level Interventions. Health Education Quarterly 12(1): 65-80.

Jervelund, S.S. (2018) How social media is transforming the spreading of knowledge: Implications for our perceptions concerning vaccinations and migrant health. Scandinavian Journal of Public Health 46: 167-169.

Johnson, M.I. and Hudson, M. (2016) Generalizing, deleting and distorting information about the experience and communication of chronic pain. Pain Management 6(5): 411-414.

Keim-Malpass, J. *et al* (2016) 'It's Back! My Remission Is Over': Online Communication of Disease Progression Among Adolescents with Cancer. Journal of Pediatric Oncology Nursing 33(3): 209-217.

Kim, H. (2014) Enacted Social Support on Social Media and Subjective Well-Being. International Journal of Communication 8: 2201-2221.

Kleinman, A. (1988) The Illness Narratives. Suffering, Healing & the Human Condition. New York: Basic Books.

Korenda, L. *et al* (2016) Will patients and caregivers embrace technology-enabled health care?. Deloitte Insights, 30 August, https://www2.deloitte.com/insights/us/en/focus/internet-of-things/digitizedcare-use-of-technology-in-health-care.html, accessed 10 March 2018.

Laestadius, L. (2017) Instagram. In: L. Sloan and A. Quan-Haase (eds.) The Sage Handbook of Social Media Research Methods. London: Thousand Oaks, pp. 573-592.

Lavorgna, L. *et al* (2017) Health-Related Coping and Social Interaction in People with Multiple Sclerosis Supported by a Social Network: Pilot Study With a New Methodological Approach. Interactive Journal of Medical Research 6(2): e10.

Magnezi, R. *et al* (2014) Online Activity and Participation in Treatment Affects the Perceived Efficacy of Social Health Networks among Patients with Chronic Illness. Journal of Medical Internet Research 16(1): e12.

McKenna, J. (2017) Social media: a powerful tool for physicians and patients. European Heart Journal, 38(7): 469-470.

Merolli, M. *et al* (2013a) Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances. Journal of Biomedical Informatics 46(6): 957-969.

Merolli, M. *et al* (2013b) Developing a framework to generate evidence of health outcomes from social media use in chronic disease management. Medicine 2.0 2(2): e3.

Merolli, M. *et al* (2015) Using Social Media While Waiting in Pain: A Clinical 12-Week Longitudinal Pilot Study. JMIR Research Protocols 4(3): e101.

Metha, N. and Atreja, A. (2015) Online social support networks. International Review of Psychiatry 27(2): 118-123.

Milani, R.V. and Lavie, C.J. (2015) Health Care 2020: Reengineering Health Care Delivery to Combat Chronic Disease. The American Journal of Medicine 128: 337-343.

Moorhead, S.A. *et al* (2013) A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication. Journal of Medical Internet Research 15(4): e85.

Nordfelt, S. *et al* (2010) Patient and Parent Views on a Web 2.0 Diabetes Portal-the Management Tool, the Generator, and the Gatekeeper: Qualitative Study. Journal of Medical Internet Research, 12(2): e17.

Obar, J.A. and Wildman S. (2015) Social media definition and the governance challenge: An introduction to the special issue. Telecommunications Policy 39(9): 745-750.

Owen, N. *et al* (2002) Communication technology and health behaviour change. In: K. Glanz, B.K. Rimer and F.M. Lewis (eds.) Health Behavior and Health Education. Theory, Research and Practice. San Francisco: Wiley & Sons, pp. 510-529.

Patel, R. *et al* (2015) Social Media Use in Chronic Disease: A Systematic Review and Novel Taxonomy. The American Journal of Medicine 128(12): 1335-1350.

PatientView (2015) What do patients and carers need in health apps – but are not getting?. eHealthNews.eu, 26 June, http://www.ehealthnews.eu/images/stories/pdf/patientview_white_paper_2015.pdf, accessed 10 March 2018.

Patient Power (2005) Connect to the Knowledge of a Community of Cancer Experts. Home Page of Patient Power, https://www.patientpower.info/, accessed 10 March 2018.

Ressler, P.K. *et al* (2012) Communicating the Experience of Chronic Pain and Illness through Blogging. Journal of Medical Internet Research 14(5): e143.

Roland, D. (2018) Social Media, Health Policy, and Knowledge Translation. Journal of the American College of Radiology 15(1, part B): 149-152.

Rus, H.M. and Cameron L.D. (2016) Health Communication in Social Media: Message Features Predicting User Engagement on Diabetes-Related Facebook Pages. Annals of Behavioral Medicine 50(5): 678-689.

Sendra, A. and Farré, J. (2017) Institutional pain communication via Twitter by Spanish and US pain societies: Analysis of levels of use and engagement. Catalan Journal of Communication and Cultural Studies 9(1): 3-23.

Urrútia, G. and Bonfill, X. (2010) PRISMA declaration: A proposal to improve the publication of systematic reviews and meta-analyses. Medicina Clínica 135(11): 507-511.

Vianna, H.D. and Barbosa, JL.V. (2017) In search of computer-aided social support in non-communicable diseases care. Telematics and Informatics 34(8): 1419-1432.

Wright, K.B. (2016a) Communication in health-related online social support groups/communities: a review of research on predictors of participation, applications of social support theory, and health outcomes. Review of Communication Research 4: 65-87.

Wright, K.B. (2016b) Social Networks, Interpersonal Social Support, and Health Outcomes: A Health Communication Perspective. Frontiers in Communication 1: article 10.

Wright, K.B. *et al* (2010) Weak-Tie Support Network Preference and Perceived Life Stress among Participants in Health-Related, Computer-Mediated Support Groups. Journal of Computer-Mediated Communication 15(4): 606-624.

5. DISCUSSION

This dissertation has been an attempt to explore the processes of pain communication through social media of both health-related organizations and patients that suffer from this complex condition. With this main purpose it has been submitted for examination in what ways communication could improve their relationship and, as a consequence, the treatment, assessment, and management of pain. The advantages and risks of these new technologies for health and the potential of using health communication theories to improve patient-physician communication have been analysed in accordance with objectives 1 and 4. The processes of communication in social media of both stakeholders have been scrutinized according to the objectives 2 and 3. In this section, the overview of results of each study are discussed and summarized. Then, at the end of the Discussion, the argumentation advances to the major limitations of this dissertation as well as suggest future lines of research to keep developing in depth this field of study.

Our first objective was to reflect both on the potential and the pros and cons of using social media platforms for pain communication in connection with the expansion of health 2.0. This is summed up in the Introductory book chapter (section 4.1). The purpose of this manuscript was to establish an initial composition of the situation, realizing a first approach to the object of study of the whole thesis. First, this paper discusses how millennials are one of the triggers of the introduction of technologies in health care, pointing out later the capability of social media for empowering users about health issues (Thackeray et al., 2012) and also for changing the healthcare model to a more patient-centered care (Hawn, 2009; Sosnowy, 2014). Then, the chapter argues about the relationship among pain and social media, highlighting how the use of these resources can result in an improvement of the well-being of the patient (Merolli et al., 2013).

Lastly, this manuscript discusses the risks of using platforms like social media for health management, indicating the concerns related to data privacy (Hawn, 2009) and the contested efficacy of these online tools (Heldman et al., 2013). This conceptual chapter, that was written during the first steps of this dissertation (i.e. late 2015, though it was finally published in 2017), raised several questions that were answered thanks to the subsequent research articles.

Our second part of the first objective was to examine the state of the art of the policies linked to communication through social media of public health organizations. In this sense, the findings in Study I (section 4.2) indicate that there is a shortage of scientific production linked to the analysis of online health communication regarding to the policies of these health institutions (Thackeray et al., 2012). This paucity of articles could be related to the reticence that health-related institutions produce towards these platforms (Lovari, 2017). Nevertheless, the studies examined mainly agree on three points: (1) there is no bidirectional communication between organizations and users (Fallon & Schmalzried, 2013); (2) these organizations share mostly non-interactive contents in a sparse way (Park, Rodgers, & Stemmle, 2011); (3) and that these online profiles are managed by non-qualified staff (Fallon & Schmalzried, 2013; Harris, Mueller, Snider, & Haire-Joshu, 2013). Previous research indicated similar findings in connection with the state of social media communication policies of food in health-related institutions (Lozano-Monterrubio, 2015).

The second objective was to study these online communication processes from the perspective of pain-related organizations. It was conducted, in particular, an analysis of the Twitter profiles from the American Pain Society and the Spanish Pain Society (section 4.3). Within the findings obtained, the results indicated that these pain institutions are in a low engagement stage, acting only as providers of health information (Neiger, Thackeray, Burton, Giraud-Carrier, & Fagen, 2013). Likewise, these organizations showed strengths in distinct areas such as hashtags use (APS), tweet typologies (SED), and targeted audiences, but in either case, they need improvements in terms of frequency, interaction with their users (SED), and better utilization of narrative content.

These results confirm the tendencies indicated in Study I. In this regard, the findings show that both the APS and the SED consider Twitter not beyond as a sheer resource for pain communication.

Nevertheless, their presence in this platform can be considered as not successful enough because both pain institutions studied are using the profiles mostly as a notice board (Thackeray et al., 2012). Moreover, since they do not share publications on a regular basis, these accounts are not generating interactions or interest among patients (Lardi, 2013).

On the other hand, the results of this study correspond with the suggestions proposed by Lupton (1995), since this unidirectional communication proves that both organizations mostly think about pain as a message. At the same time, these communication practices of the APS and the SED show that these pain organizations only consider the *disease* categorisation of malady, without considering the patients' needs (lack of interactivity, major presence of news-related and institutional content, etc.). The distance between these pain institutions and patients in social media, therefore, is doomed to increase when they communicate pain following these one-way practices.

The third objective was to analyse the communication practices of pain patients in social media spaces. Specifically, it was explored the different narratives that these individuals display on Instagram to communicate their condition (section 4.4). The whole results show that patients talk about their chronic pain in these environments quite differently from organizations; they use these Instagram posts to increase the visibility of their illnesses, to fight against the stories of restitution promoted by institutions (Frank, 1995), to reconstruct the identities that this complex condition erases (Kleinman, 1988), and to communicate pain in their own terms. These findings are consistent with the results of previous studies related to chronic pain communication in social media platforms (Gonzalez-Polledo & Tarr, 2016).

However, within these results it is also stressed that health-related professionals are mostly excluded from these narratives, and that these practices of communication are taking place only between patients. Previous studies noted that these individuals use social media to look for the support of individuals who share their similar problems (Ressler, Bradshaw, Gualtieri, & Ho Chui, 2012); but this common terrain is dilapidated with the rise of the communicative gap between patients and physicians inside these platforms. Besides, the messages from these individuals belong to the illness dimension of malady, where pain is much more than a message (Lupton, 1995). For patients, pain communication in social media is also linked to relief (Han & Wiley, 2013).

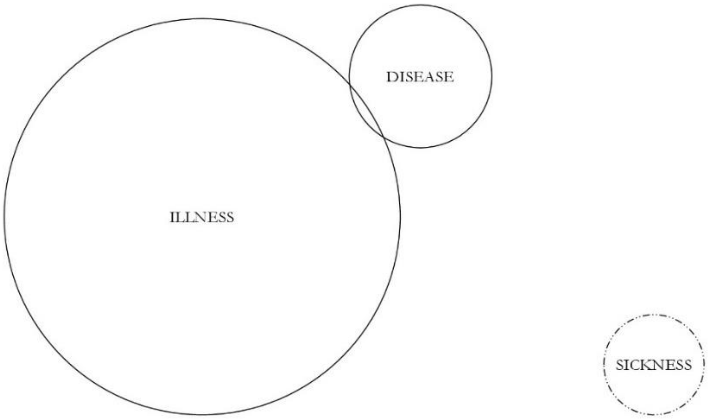
Finally, the fourth objective was to discuss at a broader level how the principles of social support theory could accommodate patient-provider interactions in social media, particularly in the field of chronic diseases. To this goal, we conducted a second systematic review of the literature with the purpose of determining the number of studies that were examining the concrete problem from this triadic search. The findings point out that there is again a paucity of papers linked to the analysis of the relation between these spaces, chronic diseases, and social support theory (section 4.5). Likewise, this shortage of scientific production could be related to the barriers that health professionals encounter when they want to use social media (Harris, Mueller, & Snider, 2013), or otherwise with the lack of serious references to these online tools in medical codes and professional routines.

Nonetheless, at last, there were identified four common points in the articles examined: (1) social media tools acquire the potential for providing patients social support on a regular basis; (2) the provision of this support works better when creating specific platforms for each disease (Lavorgna et al., 2017); (3) health professionals become key figures for the good functioning of these spaces (they need to step in social media as "natural helpers" (Heaney & Israel, 2002, p. 198)); (4) and that the interventions that are already under way must have restricted access. The latest characteristic could help health-related organizations to address the problems of privacy and related ethical concerns regarding the negligible use of social media for the management and communication of health (Roland, 2018; Rus & Cameron, 2016).

Overall, this research has analysed pain communication processes in social media of both patients and health-related institutions. In this overview, it is fair a last remark to stress how these exchanges of information look like: looking closely into the data samples extracted for examining these processes, it is detected that in these platforms there is a major presence of content created by patients (*illness*) than information produced by health institutions (*disease*). As we can observe below in Figure 1, sometimes these dimensions get in connection with each other in these platforms when interactions between patients and institutions happen inside these online tools; but the *sickness* dimension of malady is rarely discussed and does not keep connected with the rest of the approaches in these spaces.

The conflict between *disease* and *illness* in the field of chronic pain existed prior to the development of health 2.0, but these platforms have made the problem more visible to a wider public. In this sense, most of the pain information that can be found on the Internet are expressions of illness, because patients are the individuals that have been in the lead of using these technologies for complementing the self-management of this challenging condition (Gonzalez-Polledo, 2016, 2018b).

Figure 1. Pain, social media, and dimensions of malady.



In addition, although these differences between *illness* (chronic pain patients) and *disease* (health-related professionals) are more polarized in social media platforms, the findings of this thesis also show that these tools have sufficient potential to transform the current design of pain assessment policies. This would allow healthcare systems to become more efficient, profitable, and global. However, this change cannot happen at any price, and these organizations are precisely the organisms responsible for guaranteeing the digital security of patients (or the associated ethical practices). Moreover, the dangers of these spaces must not serve as an excuse for stagnation and leave aside the profound transformation in terms of opportunities. All in all, the whole results indicate that the irruption of social media are set to revolutionize the current model of health care, in particular pain care, if used responsibly.

5.1 Main limitations of this study

The limitations of each individual article (Study I, II, III and IV) are discussed inside each of these studies. Nevertheless, it deserves to stress briefly two main limitations of the selection of the samples, the empirical data generation and the biases of literature reviews.

On the one hand, the first limitation is related to the samples used for the case studies. The data gathered for conducting the analysis is extracted from different social media spaces (i.e. Instagram and Twitter). In this vein, further studies should evaluate these processes of communication between pain patients and providers in samples collected from the same platform, and counting with control groups to compare the results with patients that do not have, for instance, a social media presence.

On the other hand, the second limitation is related to the reviews executed in Study I and Study IV. Apart from the shortage of papers analysed, most of the articles discussed initiatives conducted in the United States. This could slightly bias the information regarding the health communication practices of organizations. Moreover, we do not know if these data can be considered representative of all the chronic pain community. In this sense, further systematic reviews related to pain communication and social media are needed.

Regardless of the limitations described above, this dissertation was designed for providing relevant contributions in the field of chronic pain related to the analysis of communication processes in social media, both for patients and health organizations. At this particular point, it is righteous to affirm that the purpose sought by this thesis match with the stipulated requirements in terms of the objectives reached.

5.2 Future lines of research

In this section, it is suggested a list of proposals that go beyond the results of this thesis with the desire of inspiring future research lines:

1. More studies are needed in relation to the narrative analysis of pain communication of patients in social media spaces, considering different populations (divided into age groups or by gender), with the purpose of exploring in depth how these variables could affect the practices of pain communication in these environments. In this sense, most of the existing social media spaces are generally more popular among younger populations (Tran, 2018). Besides, content analysis research related to pain communication should also explore the meanings of the images shared with the posts more deeply.

2. Further research should test the exploratory methodology created to carry out the analysis of the data in Study II in other studies linked to the practices of communication carried out by health institutions in Twitter.

3. In this dissertation it has been discussed the potential of social media platforms for pain communication, pointing out that the ties between patients are stronger than the bonds with health-related professionals. Nevertheless, the connections *per se* have not been

examined in detail. The support that pain sufferers receive from other patients through these platforms is always positive, or in what circumstances could become negative? Are the weak or strong ties between these patients in these spaces reinforcing the polarization with health professionals in social media, or perhaps the tendency could lead to the contrary? To what extent does this support wires influence pain management strategy? These multiple interrogations would allow health institutions to identify which is the best way to integrate the use of these online platforms into the management and assessment of pain.

4. Finally, future research is needed to explore the consequences of applying to social media the principles of social support theory for managing chronic diseases in the long run. This dissertation pointed out to the potential benefits of using these principles for improving the communication between patients and physicians in these spaces. Therefore, further studies should test if the development of specific pain platforms considering the guidelines of social support theory could be one of the solutions for addressing the polarization of

communication between patients and physicians in these digital networks. Moreover, by participating in social media, institutions could minimize the safety concerns linked to the use of these online spaces for health management (Lau, Gabarron, Fernandez-Luque, & Armayones, 2012); apart from educating patients to connect and interact with these resources in a more responsible way (Armayones, 2016). As evidenced by previous studies, "social support […] is an important component of health care for people with chronic health conditions" (Frohlich, 2014, p. 218). This social support could also be a significant element of social media environments.

6. CONCLUSIONS

The objectives pursued in this dissertation may be collected in four final remarks, as proposals for furthering communication centred research on chronic illnesses and pain. This recap must be perceived as wide-opening avenues to enrich health-related institutions with the challenge to strengthen wellbeing for patients:

1. From scientific literature, in the case of public health institutions, although there are evidences that point to the qualities of using these online spaces for health communication, more scientific production is needed in order to scrutinize the effectiveness of employing social media to disseminate health-related information in a more effective way. In this regard, health research and the field of communication must promote specialists who are at the frontiers of both disciplines. This field of study in construction still do not know which type of message they should share in these platforms. The task to influence positively populations with the goal of obtaining health behaviour changes is not well conceptualized, and researchers must make an effort to fill the gaps in their knowledge.

2. In innovative terms, pain-related institutions are already including social media tools as part of their communication strategies, but the impact they have use to be residual. Apart from not engaging with patients, the content they share in these platforms is not generating interest because organizations are using these tools as mere notice boards. In this vein, pain-related institutions are failing to create the support community that chronic pain patients look for otherwise in these online platforms. Nonetheless, starting from having a profile, these pain-related organizations are starting to be in the right path. The process for constructing a better and more effective presence in social media is not a short-run or simplistic task. Digital health is an unexplored territory that must be earn with perseverance and open-minded views.

3. From existing literature on pain and social media, patients who suffer from this condition stand out as one of the most active groups in these platforms. In these virtual spaces, the empowerment of pain patients contributes to understanding in which forms they are carrying out these practices of pain communication. For these

digital sufferers, the expression of their condition in social media works distinctively as a three-step process: first, there is a *breaking* (i.e. when the pain episode happens); then, there is a *reenactment* (i.e. patient's process of self-reflection to choose the means and in which platform they want to explain their pain story); and, finally, there is a *result* (i.e. the final post they share in a social media space). Besides, patients express and share their pain in different terms than health-related organizations, making visible the invisible in their narratives at appealing to the recurring problems of their complex condition. In addition, pain sufferers are using these stories to reconstruct their identities. However, these pain communication processes are only happening between patients, leaving aside both institutions as well as health-related professionals, who remain out of these practices of communication. With this heavy evidence, finding out how to fill this online communicative gap becomes a crucial research question.

4. The last but not least, a possible solution consists in incorporating social support theory as framework to be applied to social media. This theoretical strand has the capabilities to address the existing

communicative gap between patients and health professionals in these platforms. Following the principles of this theory, these spaces would be more secure both in terms of data privacy and protection, as well in terms of engaged participation of health-related providers in these ongoing processes of communication. The entry into force of the GPDR[31] data protection regulation in May 2018 (European Commission, n.d.-c) obliges health-related organizations to step up in looking for a solution to reduce the risks of pain patients in social media. At the end, health institutions and patients need to start co-designing secure spaces where these individuals find fertile terrain to benefit from the right to access to reliable information. Then, it is unavoidable for a better management of their pain that patients share experiences enriched with the help and support of health professionals, not only from sharing with other patients. However, due to the scarcity of scientific production on this subject, this field needs more detailed studies that examine the multiple implications derived from applying the principles of social support theory to these networked platforms; especially when they are used to the

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[31] General Data Protection Regulation.

interconnectedness for the management of pain or other chronic diseases. Simply put, it must be beard in mind that these conditions are often communicated poorly, but, simultaneously, most of the time they are also poorly communicated.

7. REFERENCES

Armayones, M. (2016). *El efecto smartphone: Conectarse con sentido*. Barcelona: Editorial UOC.

Bernabeo, E., & Holmboe, E. S. (2013). Patients, providers, and systems need to acquire a specific set of competencies to achieve truly patient-centered care. *Health Affairs*, 32 (2), 250-258.

Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M. (2004). The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *Annals of Family Medicine*, 2 (6), 576-582.

Breivik, H., Borchgrevink, P. C., Allen, S. M., Rosseland, L. A., Romundstad, L., Breivik Hals, E. K., … Stubhaug, A. (2008). Assessment of pain. *British Journal of Anaesthesia*, 101 (1), 17-24.

Calderón, J. L., & Beltrán, R. A. (2004). Pitfalls in health communication: Healthcare policy, institution, structure, & process. *Medscape General Medicine*, 6 (1), 9.

Centers for Diesase Control and Prevention (CDC). (2011, May 10). What is Health Communications?. *Health communication basics*. Retrieved from: https://www.cdc.gov/healthcommunication/healthbasics/WhatIsHC.html.

Cleveland Clinic (2017, January 26). *Acute vs. chronic pain*. Retrieved from: https://my.clevelandclinic.org/health/articles/12051-acute-vs-chronic-pain.

Conn, J. (2007, December 11). Health 2.0: The next generation of Web enterprises. *Modern Healthcare*. Retrieved from: https://www.modernhealthcare.com/article/20071211/INFO/312110003.

Communication. (2018, December 16). In *Merriam-Webster, Incorporated Dictionary*. Retrieved from: https://www.merriam-webster.com/dictionary/communication.

Craig, K. D. (2009). Social communication model of pain. *Pain*, 156 (7), 1198-1199.

Draper, S. (2018, September 14). iBreve: Wearable device that analyses your breathing pattern to improve stress resilience. *Wearable Technologies*. Retrieved from: https://www.wearable-technologies.com/2018/09/ibreve-wearable-device-that-analyzes-your-breathing-pattern-to-improve-stress-resilience/.

Du Pré, A. (2014). *Communicating about health: Current issues and perspectives*. New York: Oxford University Press.

Eccleston, C., Morlion, B., & Wells, C. (2018). Pain in Europe. In C. Eccleston, C. Wells, & B. Morlion (Eds.), *European Pain Management* (pp. 3-7). Oxford, UK: Oxford University Press.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196 (4286), 129-136.

European Centre for Disease Prevention and Control (ECDC). (n.d.-a). *What is health communication?*. Retrieved from: https://ecdc.europa.eu/en/health-communication/facts.

European Centre for Disease Prevention and Control (ECDC). (n.d.-b). *Health literacy*. Retrieved from: https://ecdc.europa.eu/en/health-communication/facts/health-literacy.

European Commission. (n.d.-a). Health, Demographic Change and Wellbeing. *Horizon 2020*. Retrieved from: http://ec.europa.eu/programmes/horizon2020/en/h2020-section/health-demographic-change-and-wellbeing.

European Commission (n.d.-b). Overview. *eHealth: Digital health and care*. Retrieved from: https://ec.europa.eu/health/ehealth/overview_en.

European Commission (n.d.-c). *A new era for data protection in the EU. What changes after May 2018*. Retrieved from: https://ec.europa.eu/commission/sites/beta-political/files/data-protection-factsheet-changes_en.pdf.

Eurostat (2018, November 20). *Healthcare personnel statistics – physicians*. Retrieved from: https://ec.europa.eu/eurostat/statistics-explained/index.php/Healthcare_personnel_statistics_-_physicians#Healthcare_personnel.

Fallon, L. F., & Schmalzried, H. D. (2013). A study on the responsiveness of local health departments that use Facebook. *Homeland Security & Emergency Management*, 10 (1), 1-8.

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: The University of Chicago Press.

Frohlich, D. O. (2014). The social support model for people with chronic health conditions: A proposal for future research. *Social Theory & Health*, 12 (2), 218-234.

Goldberg, D. S., & McGee, S. J. (2011). Pain as a global public health priority. *BMC Public Health*, 11, 770.

Goldingay, S. (2018). Act like it hurts: Questions of role and authenticity in the communication of chronic pain. In E. J. Gonzalez-Polledo & J. Tarr (Eds.), *Painscapes: Communicating Pain* (pp. 61-81). London: Palgrave Macmillan.

Gonzalez-Polledo, E. (2016). Chronic media worlds: Social media and the problem of pain communication on Tumblr. *Social Media + Society*, January-March, 1-11.

Gonzalez-Polledo, E. J. (2018a). Painscapes. In E. J. Gonzalez-Polledo & J. Tarr (Eds.), *Painscapes: Communicating Pain* (pp. 1-23). London: Palgrave Macmillan.

Gonzalez-Polledo, E. (2018b). Can digital health save democracy? Meeting the cosmopolitical challenge of digital worlds. *Journal of Social and Political Psychology*, 6 (2), doi:10.5964/jspp.v6i2.939.

Gonzalez-Polledo, E., & Tarr, J. (2016). The thing about pain: The remaking of illness narratives in chronic pain expressions on social media. *New Media & Society*, 18 (8), 1455-1472.

Gruzd, A. (2016). Netlytic: Software for automated text and social network analysis [Software]. Available from: https://netlytic.org/home/.

Han, J., & Wiley, J. (2013). Digital illness narratives: A new form of health communication. *Transactions of the International Conference on Health Information Technology Advancement*, 18.

Harris, J., Mueller, N., & Snider, D. (2013). Social media adoption in local health departments nationwide. *American Journal of Public Health*, 103 (9), 1700-1707.

Harris, J., Mueller, N., Snider, D., & Haire-Joshu, D. (2013). Local health department use of Twitter to disseminate diabetes information, United States. *Preventing Chronic Disease*, 10, e70.

Haseltine, W. A. (2018, April 2). Aging populations will challenge healthcare systems all over the world. *Forbes*. Retrieved from: https://www.forbes.com/sites/williamhaseltine/2018/04/02/aging-populations-will-challenge-healthcare-systems-all-over-the-world/.

Hawn, C. (2009). Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. *Health Affairs*, 28 (2), 361-368.

Heaney, C. A., & Israel, B. A. (2002). Social networks and social support. In K., Glanz, B. K., Rimer, & F. M. Lewis (Eds.), *Health behavior and health education: Theory, research and practice* (pp. 185-209). San Francisco: Wiley & Sons.

Heldman, A. B., Schindelar, J., & Weaver III, J. B. (2013). Social media engagement and public health communication: Implications for public health organizations being truly "social". *Public Health Reviews*, 35 (1), 13.

Hoffman, B. (2016). Disease, Illness, and Sickness. In M. Solomon, J. R. Simon & H. Kincaid (Eds.), *The Routledge Companion to Philosophy of Medicine* (pp. 16-26). New York and London: Routledge.

Huber, M., Knottnerus, J. A., Green, L., Van der Horst, H., Jadad, A. R., Kromhout, D., … Smid, H. (2011). How should we define health? *BMJ*, 343, d4163.

IASP (2017, December 14). *IASP Terminology*. Retrieved from: https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698.

Irving, G., Neves, A. L., Dambha-Miller, H., Oishi, A., Tagashira, H., Verho, A., & Holden, J. (2017). International variations in primary care physician consultation time: a systematic review of 67 countries. *BMJ Open*, 7, e017902.

Kleinman, A. (1988). *The Illness Narratives: Suffering, healing & the human condition*. Durham and London: Duke University Press.

Kleinman, A., Eisenberg, L., & Good, B. (2006). Culture, Illness, and Care: Clinical lessons from anthropologic and cross-cultural research. *Focus: The Journal of Lifelong Learning in Psychiatry*, 4 (1), 140-149.

Lardi, K. (2013). The social media strategy framework. In K. Lardi & R. Fuchs (Eds.), *Social Media Strategy* (pp. 17-46). Zürich: vdf Hochshulverlag AG an der ETH Zürich.

Lau, A. Y. S., Gabarron, E., Fernandez-Luque, L., & Armayones, M. (2012). Social media in health – what are the safety concerns for health consumers?. *Health Information Management Journal*, 41 (2), 30-35.

Lavorgna, L., Russo, A., De Stefano, M., Lanzillo, R., Esposito, S., Moshtari, F., … Bonavita, S. (2017). Health-related coping and social interaction in people with multiple sclerosis supported by a social network: Pilot study with a new methodological approach. *Interactive Journal of Medical Research*, 6 (2), e10.

Lovari, A. (2017). *Social media e comunicazione della salute: Profili istituzionali e pratiche digitali*. Milan: Guerini Scientifica.

Lozano-Monterrubio, N. (2015). *Critical PR in food communication and social media. The case of European food safety and promotion authorities* (Doctoral dissertation). Retrieved from Tesis Doctorales en Red (http://hdl.handle.net/10803/306264).

Lupton, D. (1995). *The Imperative of Health: Public health and the regulated body*. London: SAGE Publications.

Lupton, D. (2012). M-health and health promotion: The digital cyborg and surveillance society. *Social Theory & Health*, 10 (3), 229-244.

Lupton, D., & Maslen, S. (2017). Telemedicine and the senses: a review. *Sociology of Health & Illness*, 39 (8), 1557-1571.

Maibach, E., & Holtgrave, D. R. (1995). Advances in public health communication. *Annual Review of Public Health*, 16, 219-238.

Marr, B. (2018, May 21). How much data do we create every day? The mind-blowing stats everyone should read. *Forbes*. Retrieved from: https://www.forbes.com/sites/bernardmarr/2018/05/21/how-much-data-do-we-create-every-day-the-mind-blowing-stats-everyone-should-read/.

Martin, C. M., & Peterson, C. (2009). The social construction of chronicity – a key to understanding chronic care transformations. *Journal of Evaluation in Clinical Practice*, 15 (3), 578-585.

Mehta, N., & Atreja, A. (2015). Online social support networks. *International Review of Psychiatry*, 27 (2), 118-123.

Merolli, M., Gray, K., & Martin-Sanchez, F. (2013). Developing a framework to generate evidence of health outcomes from social media use in chronic disease management. *Medicine 2.0*, 2 (2), e3.

Merolli, M., Gray, K., & Martin-Sanchez, F. (2016). Patient participation in chronic pain management through social media: a clinical study. *Studies in Health, Technology and Informatics*, 225, 577-581.

Merolli, M., Gray, K., & Martin-Sanchez, F. (2018). TASoMe: Validating a framework to generate evidence about health outcomes from social media use. *Studies in Health, Technology and Informatics*, 247, 606-610.

National Health Service (NHS). (2016, March 1). Fibromyalgia. *Health A-Z*. Retrieved from: https://www.nhs.uk/conditions/fibromyalgia/.

Neiger, B. L., Thackeray, R., Burton, S. H., Giraud-Carrier, C., & Fagen, M. (2013). Evaluating social media's capacity to develop engaged audiences in health promotion strategies:

Use of Twitter metrics as a case study. *Health Promotion Practice*, 14 (2), 157-162.

Newhouse, N., Atherton, H., & Ziebland, S. (2018). Pain and the Internet: Transforming the experience?. In E. J. Gonzalez-Polledo & J. Tarr (Eds.), *Painscapes: Communicating Pain* (pp. 129-155). London: Palgrave Macmillan.

Newton, B. J., Southall, J. L., Raphael, J. H., Ashford, R. L., & LeMarchand, K. (2013). A narrative review of the impact of disbelief in chronic pain. *Pain Management Nursing*, 14 (3), 161-171.

OECD/EU (2018, November). *Health at a Glance: Europe 2018. State of Health in the EU Cycle*. Paris: OECD Publishing. Retrieved from: https://ec.europa.eu/health/sites/health/files/state/docs/2018_healthatglance_rep_en.pdf.

Østbye, T., Yarnall, K. S. H., Krause, K. M., Pollak, K. I., Gradison, M., & Michener, J. L. (2005). Is there time for management of patients with chronic diseases in primary care?. *Annals of Family Medicine*, 3 (3), 209-214.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwoord, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42 (5), 533-544.

Park, H., Rodgers, S., & Stemmle J. (2011). Health organizations' use of Facebook for health advertising and promotion. *Journal of Interactive Advertising*, 12 (1), 62-77.

Perdiguero, E. (2009). La salut a través dels mitjans. Propaganda sanitària institutional en l'Espanya dels anys vint i trenta del segle XX. *Mètode*, 59, 61-69.

Pericot, J. (2002). *Mostrar para decir: La imagen en contexto*. València: Universitat de Valencia; Bellaterra: Universitat Autònoma de Barcelona, Servei de Publicacions; Barcelona: Universitat Pompeu Fabra; Castelló de la Plana: Publicacions de la Universitat Jaume I.

Ressler, P. K., Bradshaw, Y. S., Gualtieri, L., & Chui, K. K. (2012). Communicating the experience of chronic pain and illness through blogging. *Journal of Medical Internet Research*, 14 (5), e143.

Rimal, R. N., & Lapinski, M. K. (2009). Why health communication is important in public health. *Bulletin of the World Health Organization*, 87, 247.

Roland, D. (2018). Social media, health policy, and knowledge translation. *Journal of the American College of Radiology*, 15 (1, part B), 149-152.

Rus, H. M., and Cameron, L. D. (2016). Health communication in social media: Messages features predicting user engagement on diabetes-related Facebook pages. *Annals of Behavioral Medicine*, 50 (5), 678-689.

Scanfeld, D., Scanfeld, V., & Larson, E. L. (2010). Dissemination of health information through social networks: Twitter and antibiotics. *American Journal of Infection Control*, 38 (3), 182-188.

Schiavo, R. (2007). *Health communication: From theory to practice (1st edition)*. San Francisco: Jossey-Bass.

Sendra, A. (2017). Social media and new communication strategies to pain information [Los social media y las nuevas estrategias de comunicación de la información ante el dolor]. In J. M. Comelles & E. Perdiguero (Eds.), *Educación, comunicación y salud: Perspectivas desde las ciencias humanas y sociales* (pp. 227-244). Tarragona: Publicacions URV.

Sendra, A., & Farré, J. (2016). Public health institutions and social networks: a systematic review. *Revista Española de Comunicación en Salud*, 7 (2), 285-299.

Sendra, A., & Farré, J. (2017). Institutional pain communication via Twitter by Spanish and US pain societies: Analysis of levels of use and engagement. *Catalan Journal of Communication & Cultural Studies*, 9 (1), 3-23.

Sharf, B. F., & Vanderford, M. L. (2008). Illness narratives and the social construction of health. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.), *Handbook of Health Communication* (2nd ed., pp. 9-34). Mahwah, NJ: Lawrence Erlbaum Associates.

Societal Impact Pain Platform (SIP-Platform) (2017, May 24). *Impact of pain on society costs the EU up to 441 billion euros annually*. Retrieved from: https://www.sip-platform.eu/press-area/article/impact-of-pain-on-society-costs-the-eu-up-to-441-billion-euros-annually.

Sosnowy, C. (2014). Practicing patienthood online: Social media, chronic illness, and lay expertise. *Societies*, 4, 316-329.

Tarr, J. (2018). Painscapes and method. In E. J. Gonzalez-Polledo & J. Tarr (Eds.), *Painscapes: Communicating Pain* (pp. 229-248). London: Palgrave Macmillan.

Thackeray, R., Neiger, B. L., Smith, A. K., & Van Wagenen, S. B. (2012). Adoption and use of social media among public health departments. *BMC Public Health*, 12, 242.

Torkkola, S. (2009, August). *Health and illness in health journalism: how to analyze them*. Paper presented at the 19th Nordic Conference on Media and Communication Research, Karlstad, Sweden.

Torkkola, S. (2013, November 14). Health communication in social media 2011-2015. Retrieved from: http://www.uta.fi/cmt/tutkimus/comet/yhteystiedot/torkkola/english/healthcommunication.html.

Tran, K. (2018, March 5). Social platforms are most popular among 18- to 29-year-olds. *Business Insider*. Retrieved from: https://www.businessinsider.com/social-platforms-are-most-popular-among-18-to-29-year-olds-2018-3.

United Nations. Department of Economic and Social Affairs (UN DESA). (2017, June 21). *World population projected to reach 9.8 billion in 2050, and 11.2 billion in 2100*. Retrieved from: https://www.un.org/development/desa/en/news/population/world-population-prospects-2017.html.

Urrútia, G., & Bonfill, X. (2010). PRISMA declaration: A proposal to improve the publication of systematic reviews and meta-analyses. *Medicina Clínica*, 135 (11), 507-511.

Van Hecke, O., Torrance, N., & Smith, B. H. (2013). Chronic pain epidemiology – where do lifestyle factors fit in?. *British Journal of Pain*, 7 (4), 209-217.

Walsh, J., Eccleston, C., & Keogh, E. (2014). Pain communication through boy posture: The development and validation of a stimulus set. *Pain*, 155 (11), 2282-2290.

Williams, B. (2017, August 7). There are now over 3 billion social media users in the world – about 40 percent of the global population. *Mashable*. Retrieved from: https://mashable.com/2017/08/07/3-billion-global-social-media-users/?europe=true.

Wolfe, F., Clauw, D. J., Fitzcharles, M. A., Goldenberg, D. L., Katz, R. S., Mease, P., … Yunus, M. B. (2010). The American College of Rheumatology preliminary diagnostic criteria for fibromyalgia and measurement of symptom severity. *Arthritis Care & Research*, 62 (5), 600-610.

World Health Organization (WHO). (n.d.-a). Constitution of the World Health Organization. *Constitution*. Retrieved from: http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf?ua=1.

World Health Organization (WHO). (n.d.-b). Health promotion. *Health topics*. Retrieved from: https://www.who.int/topics/health_promotion/en/.

World Health Organization (WHO). (2016, n.d.). *Global strategy on human resources for health: Workforce 2030*. Retrieved from: https://www.who.int/hrh/resources/global_strategy_workforce2030_14_print.pdf?ua=1.

Wright, K. B., Sparks, L., & O'Hair, H. D. (2008). *Health communication in the 21st century*. Oxford, UK: Blackwell Publishing.

8. APPENDIXES

8.1 Codification process of Study II

Variable 1: Content

Variable 1a: Tweet typologies

1. Profile tweets
2. Retweets[i]
3. Answers
4. Quote tweets

Variable 1b: Topics

1. News-related tweets
2. Institutional tweets
3. Educational tweets
4. Science community tweets

Variable 1c: Number of images

Add manually

Variable 1d: Number of videos

Add manually

Variable 1e: Number of links

Add manually

Variable 2: Interactivity

Variable 2a: Number of user interactions

Add manually

Variable 2b: Number of retweets

Add manually

Variable 2c: Number of likes

Add manually

Variable 3: Hashtags

Variable 3a: Number of hashtags

Add manually

Variable 3b: Hashtags used

Add manually

Variable 4: Targets

1. Internal targets
2. External targets

Variable 5: Frequency

Add manually

Variable 6: Pain-related tweets

1. Pain-related
2. Non-pain related

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[i] Extra variable inside the variable 1a (Retweets subcategory)

Variable 1ab: Endorsed profiles

1. Health professionals
2. Institutions and associations
3. Media and journalists
4. Educationals
5. Others

8.2 Codification process of Study III

Variable 1: Illness narrative typology

1. Restitution
2. Chaos
3. Quest

Variable 2: Use of the illness narrative

1. Construction of an illness world
2. Reconstruction of life history
3. Explanation/understanding of illness
4. Strategic device
5. Transformation to a collective experience

Variable 3: Kind of pain (typologies)

Add manually

Variable 4: Kind of visual representations used (typologies)

1. Photo
2. Illustration

3. Boomerang

4. Video

Variable 5: Photographic frame of the persons depicted

1. Face/face and body

2. Body/body part

3. Other (treatment, meme, etc.)

4. No frame (illustration, etc.)

Variable 6: Gender of the owner of the profile

1. Man

2. Woman

Variable 7: Number of likes

Add manually

Variable 8: Number of comments

Add manually

Variable 9: Pain narrative typology

1. Generalization

2. Deletion

3. Distortion

Variable 10: Coping strategy

1. Problem-focused

2. Emotional-focused

3. Avoidance-focused

Variable 11: Level of uncertainty

1. Negative

2. Positive

3. Neutral

4. Combined

Variable 12: Use of metaphors to express illness/pain

Add manually

Variable 13: References to health professionals

Add manually

Variable 14: Level of private information sharing

1. Low

2. Medium

3. High

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