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**Online reputation management in Spanish cancer patients' associations:
a proposal model**

***La gestión de la reputación online en las asociaciones españolas de
enfermos de cáncer: una propuesta de modelo***

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Abstract

Cancer patients' associations have become valid public health players because they help patients to face this disease from physical, emotional and social perspectives. Some of these associations resort to social media platforms not only to improve their relationships with patients, but also to promote their own brand. This paper seeks to understand how Spanish cancer patients' associations manage their social media platforms to promote their brand. To do that, we conducted a literature review about health communication; we considered 48 indicators to analyze how 107 associations belonging to the Spanish Group of Cancer Patients (Gepac) managed Facebook, Twitter, Youtube and their corporate website for branding initiatives; and we proposed a communication model for branding cancer patients' associations on these platforms (MedPac Model). We concluded that Spanish cancer patients' associations prioritize medical information but not brand-related elements, they lack the economic and human resources to produce a quality content, and they have not yet implemented a true corporate communication approach.

Keywords

Cancer Patients' Associations; Corporate Communication; Brand; Reputation; Social Media

Resumen

Las asociaciones de enfermos de cáncer se han convertido en un verdadero actor de salud pública ya que ayudan a los pacientes a afrontar esta enfermedad desde un punto de vista físico, emocional y social. Algunas de estas asociaciones recurren a las redes sociales para mejorar sus relaciones con los pacientes, así como para promocionar su propia marca. Este artículo tiene como objetivo comprender cómo las asociaciones españolas de pacientes con cáncer gestionan sus redes sociales para promover su marca. Para ello, realizamos una revisión de literatura sobre comunicación en salud; recurrimos a 48 indicadores para analizar cómo las 107 asociaciones pertenecientes al Grupo Español de Enfermos de Cáncer (Gepac) gestionaban Facebook, Twitter, Youtube y su web corporativa para promocionar su marca; y finalmente proponemos un modelo de comunicación para ayudar a dichas asociaciones a promocionar su marca en las redes sociales (Modelo MedPac). Concluimos que las asociaciones españolas de enfermos de cáncer priorizan la información médica pero no la arquitectura de marca, carecen de los recursos económicos y humanos necesarios para producir contenidos de calidad, y no implementan un verdadero enfoque de comunicación corporativa.

Palabras clave

Asociaciones de Pacientes de Cáncer; Comunicación Corporativa; Marca; Reputación; Redes Sociales

1. Introduction

The social impact of cancer, as well as the physical and psychological consequences for patients and their relatives, lead many years ago different patients, doctors and nurses all over the world to develop different patients' associations. They pioneer these associative movements in medical contexts, from an organizational point of view, but also from a communication standpoint: events, magazines, websites, etc. Cancer patients' associations have become a true public health player. They help patients through many different initiatives such as health education programs, legal and medical counseling, awareness campaigns about different diseases and emotional support networks. Cancer patients face challenging situations from a physical, emotional and social point of view. Cancer constitutes a true trauma for many of them: lack of knowledge and experience about this disease, uncertainty, social rejection. Managing these patients constitutes a challenge for patients' associations, but also for other health organizations such as hospitals or public authorities. Most of them resort to social media platforms to help patients deal with cancer, but also to promote their own corporate brand. This paper aims to evaluate how Spanish cancer patients' associations manage social media platforms to promote their brand reputation. To do that, we conducted a literature review about health communication, brand, social media and patient's associations; then, we considered 48 indicators to analyze how 107 associations belonging to the Spanish Group of Cancer Patients (Gepac) managed Facebook, Twitter, Youtube and their corporate website for promoting their brand; and finally, we proposed a communication model for branding these associations on social media platforms (*MedPac Model for Branding Cancer Patients Association*). Our results help cancer associations to improve their social media presence and also constitute a starting point for other patients' associations specialized in other diseases, even if these last ones should develop their own online communication models.

2. Literature Review

The professional management of corporate communication has become a priority for health organizations, especially hospitals, patients' associations and public health authorities (Hannawa et al., 2015). Thanks to corporate communication, these organizations improve their own internal functioning as well as their relationships with stakeholders: employees, patients, suppliers, media companies (Brent, 2016). Developing corporate communication in health organizations constitutes an opportunity to improve patients' skills in different domains (health education, health literacy) as well as their perceptions about health-related issues (Jones et al., 2015; Weberling, 2014). Health organizations focus their communication initiatives on three main areas: interpersonal, internal and external communication.

Interpersonal communication refers to all initiatives implemented by health organizations to help their employees interact with each other –and with some external stakeholders– in a more performant way (Gilligan et al., 2016). For example, hospitals train their doctors on interpersonal communication skills in order to help them listen to patients in a more efficient way (Jahromi et al., 2016), establish with patients rich relationships based on human values (Brent, 2016) and convince patients to follow treatments and medical advices (Archiopoli et al., 2016). As to internal communication, it embraces all initiatives carried out to share organizational content, improve internal processes (Rodrigues, Azevedo & Calvo, 2016) and promote the company's brand architecture -identity, mission, vision, values and culture- (Medina Aguerrebere, 2020). Finally, external communication involves different actions addressed to influence external stakeholders' perceptions about the health organization, its employees and services (Pelitti, 2016). One of the most important targets for external communication initiatives are patients because, on the one hand, they are true opinion leaders able to influence other citizens' perceptions (Becerra, Reina & Victoria, 2015); and, on the other hand, they own different rights that should be respected by health organizations (Maier, 2016).

When implementing interpersonal, internal and external communication initiatives, health organizations resort to social media platforms (Matarín Jiménez, 2015). To do that in a professional way, they employ experts in corporate communication who disseminate meaningful content that satisfy stakeholders' needs and reinforce the company's brand (Ruiz-Granja, 2015). They define budgets and protocols (Rando Cueto & de las Heras Pedrosa, 2016), as well as different key performance indicators to monitor and evaluate all initiatives launched on these platforms (Abramson, Keefe & Chou, 2015). Thanks to social media, health organizations implement collective decision-making processes along with patients (Lim, 2016), reinforce patients' empowerment (Fischer, 2014), establish a dialogue with different targets focused on health education initiatives (Visser et al., 2016), and accelerate their digital transformation in order to become more performant (Househ, Borycki & Kushniruk, 2014).

Patients have become one of the most active users on social media (Medina Aguerrebere, Gonzalez Pacanowski & Medina, 2020). Thanks to these platforms, they search for medical information about treatments or diseases, share their health experiences and build an

emotional support network (Myrick et al., 2016). Social media have become a true source of medical information that determines patients' decisions concerning the adherence to the treatment (Badr, Carmack & Diefenbach, 2015). Hospitals acts as health education in their social media platforms (Costa-Sánchez, Túnñez-López & Videla-Rodríguez, 2016), which can lead other organizations to do the same, such as patients' associations. These online experiences determine patients' behaviours and attitudes when they interact with health professionals at hospital (Namkoong et al., 2017): their communication relationships become friendlier and more respectful because patients and doctors can dialogue (Smailhodzic et al., 2016).

There is not a direct relation between a country's health resources and its hospitals' presence on social media platforms (Busto Salinas, 2021). Nevertheless, thanks to these platforms, health organizations implement different initiatives to reinforce their brand (Medina Aguerrebere, 2020). This corporate element represents tangible and intangible values that influence stakeholders' perceptions about the company (Esposito, 2017). Health organizations implement branding initiatives to reinforce their strategic positioning in the market and this way adapt to the changing context in a performant way (Kemp, Jilipalli & Becerra, 2014). Building a strong brand is essential to reinforce their reputation as well as their social legitimacy as health providers (Blomgren, Hedmo & Waks, 2016). On the other hand, patients face complicated situations from an emotional point of view (disease, uncertainty), that is why many health organizations prioritize an emotional approach when using social media for branding purposes (Maier, 2016). Respect, ethics, empathy and trust are some of the emotional values used by these organizations to build a credible brand (Trong, 2014).

When evaluating health organizations' brands and reputation, stakeholders consider different criteria including their presence on social media platforms: interactions, scientific information disseminated, initiatives proposed to patients (Huesch, Currid-Halkett & Doctor, 2014). Some organizations also resort to online communities to promote their brands and reinforce their engagement with stakeholders (Liu et al., 2014). Using social media constitutes an opportunity because health organizations can analyze stakeholders' needs and expectations (Fernández-Gómez & Díaz-Campo, 2016); but also a risk since some patients can react negatively and criticize these organizations, their employees or services (Lagu et al., 2016). Two of the most important platforms used by health organizations are *Facebook* and *Twitter* (Triemstra, Stork & Arora, 2018): on both platforms, patients read about general health issues, share personal experiences and interact with doctors (Costa-Sánchez & Míguez-González, 2018). Health organizations also resort to more visual and interactive social media platforms such as *Youtube* in order to disseminate medical information and help patients reinforce their empowerment (Basch et al., 2015; Kotsenas et al., 2018).

In Spain, health organizations are really active on social media platforms, especially hospitals, public authorities and patients' associations (Medina Aguerrebere, 2019). With respect to the last ones, there are 1904 patients' associations, most of them in Madrid -448-, Barcelona -201- and Valencia -76- (Somos Pacientes, 2021). One of the leading patients' associations is *Foro Español de Pacientes*, founded in 2004, integrated by 68 associations and specialized in education and research initiatives addressed to patients (Foro Español de Pacientes, 2021). In Spain, patients' associations have become a true source of medical information, as well as a platform for patients to share their experiences (Almodóvar, Gratacós & Zarco, 2018). Thanks to these associations, health organizations in Spain – especially hospitals and public authorities- become more transparent and efficient, what positively influences on their reputation and on patients' satisfaction (Sánchez Fierro, 2019).

3. Methodology

In order to better understand how Spanish cancer patients' associations manage their social media platforms and websites to implement branding initiatives, we resorted to the official ranking of cancer patients' associations belonging to the Spanish Group of Cancer Patients (*Grupo Español de Pacientes con Cancer*, GEPAC). Rankings scales are an important too that serves learning outcomes, improve global competition and enhance organizations' policies (Ali, 2022). GEPAC groups the main Spanish cancer patients' associations. Founded in 2020, GEPAC integrates different associations specialized: rare tumors, breast, head and neck, liver, pancreas, prostate, lung, kidney, skin and melanoma. In January 2021, GEPAC was integrated by 107 associations (see Annex 1 List of Cancer Patients Associations).¹

From 28th March to 23rd April 2021, we conducted a quantitative analysis on how Spanish Cancer Patients' Association belonging to GEPAC managed *Facebook*, *Twitter*, *Youtube* and their own corporate website for branding initiatives. We focused on how they managed each platform from a corporate point of view, regardless of the unusual crisis situation provoked by Covid 19. Even if corporate websites allow health organizations to centralize their online communication strategies and reinforce their relationships

with stakeholders (Sedrak et al., 2016), these organizations also resort to *Facebook*, the most important social media platform with more than 2.7 billion monthly active users in December 2020 (Statista, 2021); *Twitter*, one of the most useful platforms for engaging active conversations with patients (Park, Reber & Chon, 2016); and *Youtube*, the best social media for disseminating visual information related to health, treatments and diseases (Balasooriya-Smeekens, Walter & Scott, 2015).

In order to evaluate how Spanish cancer patients' associations managed their *Facebook*, *Twitter*, *Youtube* and their website for branding initiatives, we defined 48 key indicators grouped in three categories: a) identity, b) communication activities and c) patients' engagement (see *Table 1. Key Indicators*). As to identity, the logo presents the organization's identity (Alkibay, Ozdogan & Ermec, 2007), links between the company's website and its social media platforms increase the impact of the organization's online branding initiatives (Antheunis, Tates & Nieboer, 2013), and explaining corporate elements -mission, vision, values and awards- allows organizations to justify their brand uniqueness (Cady et al., 2011). According to Moore et al., (2018), cancer patients have a high prevalence of stress and need clear information, that is why using different tools such as engines for finding doctors (professional background, specializations, phone number, email, etc.) and diseases, links to research and education departments, and corporate descriptions about the patients' association and its main milestones contributes to improve the patient's experience and so the organization's image. Resorting to multilingual websites, doctors' pictures and hashtags also facilitates this process. Concerning communication activities, using videos, press releases, online events and facilitating contacts with media companies is essential to professionalize organizations' corporate communication strategies on social media platforms (Taken, 2017). Finally, with respect to patients' engagement, mobile apps and patients' platforms make users' experiences more customized, which positively impacts on the organization's image (Prochaska, Coughlin & Lyons, 2017).

These indicators allowed us to evaluate whether associations shared brand-related content. We have as much as possible tried to homogenize all indicators in the four platforms; nevertheless, we also considered some particular kind of data provided by each platform. We only analyzed corporate profiles, and not those that some associations use for events or for some departments. On each profile, we only considered inputs that we could immediately identify on the homepage or the *About Us* Section, and not those for which we needed to do more than one click and browser in different menus.

To summarize, we focused on 107 analyze units (associations), 4 variables (*Facebook*, *Twitter*, *Youtube*, website) and three main categories (identity, communication activities and patient's engagement). All key indicators were analyzed according to the binary system, except seven of them that were analyzed as absolute numbers: *Facebook* (11, 12), *Twitter* (9,11,12) and *Youtube* (11,12).

Table 1. Key Indicators

Corporate Website	Facebook	Twitter	Youtube
Identity*			
1. Corporate logo	1. Corporate logo	1. Corporate logo	1. Corporate logo
2. Multilingual website	2. Links to corporate websites	2. Links to corporate websites	2. Links to corporate websites
3. About Us section	3. Corporate description	3. Corporate description	3. Corporate description
4. Find a doctor	4. Milestones	4. Joined date	4. Milestones
5. Find diseases	5. Awards	5. Foundation date	5. Awards
6. Links to research and education departments	6. Brand values	6. Hashtags in the description	6. Brand values
7. Link to the Press Department	7. Mission	7. Health professionals or associations' buildings in the main image	7. Mission
8. Links to social media platforms	8. Vision	8. Links to other social media platforms	8. Vision

Communication Activities**			
9. Videos in the homepage	9. Videos integrated	9. Number of Followings	9. Playlists
10. Press releases in the homepage	10. Events	10. Media section with videos	10. Channels
Patient's engagement***			
11. Patients' platform	11. Number of likes	11. Number of likes	11. Number of subscribers
12. Mobile apps	12. Number of followers	12. Number of followers	12. Number of views

Source. Authors' elaboration.

*Homepage in the Corporate Website and Twitter; and About Us Section in Facebook and Youtube.

** Homepage in all platforms.

*** Homepage in all platforms.

4. Results

Spanish cancer patients' associations resort to corporate websites and social media platforms (Facebook, Twitter and Youtube) to implement branding initiatives allowing them to reinforce their relationships with internal and external stakeholders. After evaluating how these organizations manage these platforms, we present our quantitative results grouped in four main blocs.

Corporate websites. According to our results, 72,89% of Spanish cancer patients' associations have a corporate website. Most of them respect many criteria related to *identity*: corporate logo on the homepage (100%), About Us section (96%), links to social media platforms (81%), links to research and education sections (77%), search engines for finding diseases (44%), links to the Communication Department (18%), multilingual website (5%) and search engines for finding doctors (0%). With respect to *communication activities*, 45% of associations display videos on their homepage and 65% also publish press releases. Concerning *patient's engagement*, most associations do not respect these criteria: no one have a patient platform and only 1% propose a mobile app. Finally, 65,38% of Spanish cancer patients' associations respect between 4 and 5 indicators (See Table 2. *Indicators Distribution*), and the only one fulfilling 9 criteria is Asociación de Micropigmentación Estética, Paramédica y Oncológica.

Table 2. Indicators distribution

Number of indicators	Number of associations
12	0
11	0
10	0
9	1
8	3
7	8
6	21
5	14
4	16
3	6
2	8
1	1
0	0

Source. Authors' elaboration.

Facebook. 83,18% of Spanish cancer patients' associations resort to Facebook to disseminate their brand. Some of them do not have a corporate website, but they have a Facebook profile; other associations have both of them, but they do not display a Facebook link on their corporate website; and other associations display this link, but their profile on Facebook is not activated anymore; finally, some associations use the same Facebook profile (see Table 3 below). Concerning *identity*, most associations do not fulfill these criteria: corporate logo on their main profile image (97%), links to other corporate websites (97%), corporate description (71,91%), main milestones (6,74%), mission (1,12%), awards (0%), brand values (0%) and vision (0%). With respect to *communication activities*, 88,89% of associations show videos on their corporate website and 75% also display and Event Section where different events and press releases related to the association are promoted. As to *patients' engagement*, *Fundación Cris Contra el Cáncer* is the most reputed Spanish cancer patients' association on Facebook according to the number of likes and followers (see Table 3. *Associations by likes and followers*). Finally, concerning *identity* and *communication activities* indicators, 76,40% of associations respect between 4 and 5 indicators, and the only fulfilling 7 criteria is *Asociación Oncohematológica*.

Table 3. Associations by likes and followers

	Association	Number of likes	Number of followers
1	Fundación Cris Contra el Cáncer	140 897	141 175
2	Fundación Sandra Ibarra de Solidaridad Frente al Cáncer	15 778	15 730
3	División Cáncer de Hígado España, División Cáncer de Páncreas España, División Cáncer de Piel y Melanoma España, División Cáncer de Pulmón España, División Cáncer de Riñón España and División Cáncer de Vejiga España.*	11 868	12 265

Source. Authors' elaboration.

* All of them share the same Facebook Profile (Gepac).

Twitter. Our results show that only 47,66% of Spanish cancer patients' associations have a corporate profile on this platform. Some of them have a profile on Twitter, but they do not show the link on their corporate website; other associations show this link, but their Twitter profile is not activated anymore; finally, some associations share the same Twitter profile (see Table 4 below). Concerning *identity*, some associations respect many of these criteria: date when they joined Twitter (100%), links to corporate websites (96,10%), logo on the main profile image (92%), corporate description (66,67%), hashtags on their description (41,17%), health professionals or buildings belonging to the association as main profile image (33,33%), foundation date (3,92%) and links to other social media platforms (3,92%). As to *communication activities*, 98% of associations display a Media Section, and the best ones in terms of following are those sharing the same Twitter profile (Gepac): *División Cáncer de Hígado España*, *División Cáncer de Páncreas España*, *División Cáncer de Piel y Melanoma España*, *División Cáncer de Pulmón España*, *División Cáncer de Riñón España* and *División Cáncer de Vejiga España* (3 304 followings). Concerning *patients' engagement*, the best association in terms of number of likes is *Asociación De Afectados Por Cáncer De Ovario* (see Table 4 below) and the best ones in terms of number followers are also those sharing the same Twitter profile -Gepac- (15 800 followers).

Table 4. Associations by number of likes

	Association	Number of likes
1	Asociación De Afectados Por Cáncer De Ovario	7 568
2	División Cáncer de Hígado España, División Cáncer de Páncreas España, División Cáncer de Piel y Melanoma España, División Cáncer de Pulmón España, División Cáncer de Riñón España and División Cáncer de Vejiga España*	5 525
3	Asociación De Familias Afectadas Por El Síndrome De Lynch	5 086

	Association	Number of likes
4	Rosae	4 832
5	Asociación Para La Lucha Contra La Leucemia De La Comunidad Valenciana	4 510

Source. Authors' elaboration.

* All of them share the same Twitter Profile (Gepac).

Youtube. Only 32,71% of associations resort to *Youtube* as a corporate communication tool. Some associations do not have a corporate website, but they use *Youtube* for branding initiatives; other associations have both of them, but they do not display a *Youtube* link on their corporate website; finally, other associations share the same *Youtube* profile (see Table 5 below). With respect to *identity*, most associations do not fulfill these criteria: logo on their main profile image (94%), links to corporate websites (40%), corporate description (28,57%), mission (8,57%), milestones (5,71%), awards (0%), brand values (0%) and vision (0%). As to *communication activities*, 54% of associations propose playlists and 17,14% displays channels. With respect to *patients' engagement*, the best association according to the number of subscribers is *Fundación Cris Contra el Cáncer* (see Table 5 below), and the best ones by number of views are *Asociación Española De Cáncer De Tiroides* (994 460), *Fundación Cris Contra el Cáncer* (494 394) and *Asociación Española De Adolescentes Y Adultos Jóvenes Con Cáncer* (368 770). Finally, concerning *identity* and *communication activities* indicators, 68,57% of associations respect between 1 and 3 indicators, and the only two associations fulfilling six indicators are *Fundación Cris Contra el Cáncer* and *Asociación Pitiusa de Ayuda a Afectados de Cáncer*.

Table 5. Associations by number of subscribers

	Association	Number of subscribers
1	Fundación Cris Contra el Cáncer	1 350
2	Asociación Española De Adolescentes Y Adultos Jóvenes Con Cáncer	878
3	División Cáncer de Piel y Melanoma España, División Cáncer de Vejiga España*	715
4	Asociación Oncológica Extremeña	436
5	Fundación Sandra Ibarra de Solidaridad Frente al Cáncer	306
6	Asociación Infantil Oncológica de Madrid	204
7	Asociación De Afectados Por Cáncer De Ovario	113
8	Asociación de Cáncer de Mama de Tenerife	82
9	Asociación Candela Riera	76

Source. Authors' elaboration.

* Both of them share the same *Youtube* Profile (Gepac).

Finally, we analyzed the engagement rate of cancer patients' associations on *Facebook*, *Twitter* and *Youtube*. This rate has been used by different authors to evaluate how companies engage with their stakeholders on *Youtube* (López-Navarrete et al., 2021), and can also be applied to other social media platforms. The formula used to calculate this rate is: number of interactions divided by number of followers, and multiplied by 100. Based on this formula, we identified the best patients' associations in each platform according to the rate engagement (see table 6. *Engagement rate*).

Table 6. Engagement rate

Social media platform	Patients' association	Engagement rate
Facebook*	Grupo De Investigación En Actividad Física Y Salud	105,18
	Asociación Española De Afectados Por Linfoma, Mieloma y Leucemia	102,03
	Asociación De Personas Con Linfedema En Aragón	101,79
	Asociación Oncohematológica	100,95
	Asociación De Familiares Y Enfermos De Torrevieja	100,52
	AVÍVATE - Asociación de salud a través del ejercicio físico y ocio para pacientes oncológicos	1.149,41
Twitter**	ROSAE	835,98
	Asociación De Familias Afectadas Por El Síndrome De Lynch	638,14
	Asociación Para La Lucha Contra La Leucemia De La Comunidad Valenciana	521,38
	Asociación de Pacientes con Tumores Neuroendocrinos	422,50
	Asociación Española De Adolescentes Y Adultos Jóvenes Con Cáncer	42.001,13
Youtube***	Dona Médula Aragón	40.250
	Fundación Cris Contra el Cáncer	36.621,77
	Asociación Onubense de Cáncer de Mama "Santa Águeda"	36.139,13
	Asociación Comarcal De Personas Afectadas Por El Cáncer	32.522,72

Source. Authors' elaboration.

* Facebook. (Number of likes/ number of followers) X 100

** Twitter. (Number of likes/number of followers) X 100

*** Youtube. (Number of views/number of subscribers) X 100

5. Discussion

Spanish cancer patients' associations resort to social media platforms to disseminate medical and organizational information. Nevertheless, most of them do not use these platforms for branding initiatives. Social media are essential to better understand how patients conceptualize their specific health issues and why they interact with doctors in a particular way (Sedrak et al. 2016). This knowledge is crucial to make patients associations' corporate communication initiatives more performant (Medina, Gonzalez Pacanowski & Medina, 2020). Cancer patients' associations in Spain should manage social media platforms in a more professional way, which includes defining four key elements: a) communication objectives, b) main and secondary targets, c) brand positioning and d) evaluation system based on key performance indicators. Defining these strategic elements is mandatory before implementing any initiative on social media platforms.

Communication objectives. Defining realistic, achievable objectives that guide the organization and reduce risks is in Spain have a corporate website (72,89%) and a Facebook profile (83,18%); nevertheless, few of them the first step when implementing a corporate communication campaign (Zerfass & Viertmann, 2017). Organizations should carry out quantitative and qualitative research for setting their communication objectives and strategies (Túñez-López, Costa-Sánchez & González, 2018). According to our results, most cancer patients' associations resort to *Twitter* (47,66%) and *Youtube* (32,71%). On the other hand, when it comes to the corporate website, 65,38% of Spanish cancer patients' associations only respect between 4 and 5 indicators; and on *Facebook*, no one explains their vision, brand values or

corporate awards. Using actively these four platforms for disseminating brand elements in a professional way should be a mandatory communication objective for all Spanish Cancer Patients' Associations.

Main and secondary targets. Health organizations resort to social media platforms to communicate with many different targets such as employees, patients, journalists, public authorities and shareholders (Park, Reber & Chon, 2016). These organizations should especially consider media companies' needs in terms of information and based on that, share on social media content useful for journalists (Esparcia, Villafranca & Carretón-Ballester, 2015). According to our results, most Spanish cancer patients' associations focus their communication on patients, even if they also consider other targets such as journalists (65% publish press releases on their corporate website, 98% have a media section on *Twitter*), researchers (77% display on their website a link to research and education sections), and society (75% show an event section on *Facebook* to inform society about different cultural events, and 54% propose on *Youtube* different playlists about health-related topics).

Brand positioning. Health organizations disseminate meaningful content in order to influence stakeholders' perceptions and create a reputed, credible brand (Kemp, Jillapalli & Becerra, 2014). Our results show that most Spanish cancer patients' associations can still improve how they disseminate brand-related content: no association proposes a patients' platform on their corporate website, no one present their brand values and vision on *Youtube*, only 6,74% explain on *Facebook* their corporate milestones, and barely 3,92% integrate *Twitter* with other corporate platforms. To reinforce their brand and influence stakeholders' perceptions, cancer patients associations should be present on the three platforms considered (*Facebook*, *Twitter* and *Youtube*).

Evaluation. Health organizations use different key performance indicators to evaluate how employees disseminate brand-related elements through social media platforms (Sutton et al., 2018). Spanish cancer patients' associations resort to different criteria to evaluate their stakeholders' engagement: website (number of people using mobile apps and patients' platforms), *Facebook* (number of likes and followers), *Twitter* (number of likes and followers) and *Youtube* (number of subscribers and views). Based on these criteria, one of the best associations is *Fundación Cris Contra el Cáncer* (*Facebook*, *Youtube*). In order to build a true reputed brand, these associations should consider how patients interact with their platforms (websites, *Facebook*, *Twitter* and *Youtube*) from a quantitative point of view (likes, views, etc.), but also from a qualitative point of view (kind of content, shares, questions, comments, etc.). Cancer patients associations should regularly evaluate their engagement rate on *Facebook*, *Twitter*, and *Youtube* and identify the contents, events and other communication initiatives that are the most efficient to engage with stakeholders.

Our quantitative analysis shows that most Spanish cancer patient's associations focus their content on medical and organizational information and not on brand-related elements. Besides, they do not have the means to efficiently manage many social media platforms at the same time. And, they lack a professional approach when it comes to efficiently integrate all these platforms in order to influence stakeholders' perceptions. Based on these quantitative inputs, as well as the previous literature review that we carried out, we propose the *MedPac Model for Branding Cancer Patients' Association*. This model includes four main elements: a) Social Media Department, b) communication principles, c) annual content plan (brand architecture, messages, target and platform) and d) key performance indicators.

Social Media Department. Cancer patients' associations implement a department specialized on using social media platforms for disseminating medical and organizational information allowing them to promote their brand architecture (identity, mission, vision, values and culture). This department employs experts in corporate communication, public health, social media and artificial intelligence. This department is led by a Social Media Manager whose main responsibility consists of defining and implementing an annual online communication plan based on different protocols and key performance indicators. The Social Media Manager reports directly to the hospital's Corporate Communication Director.

Communication principles. In order to improve their communication relations with patients when using social media platforms, cancer patients' associations could consider these ten principles. First, integrating *human values*, such as respect, trust or politeness, in order to establish enriching relationships with stakeholders (Smailhodzic et al., 2016). Second, implementing a *public health approach* based on patient's needs in terms of information and emotional support (Miller, Guidry & Fuemmeler, 2019). Third, respecting *medicine basic principles* such as patient's rights, privacy or collective decision-making processes (Kotsenas et al., 2018). Fourth, disseminating *accurate information* allowing the organization to become a credible brand from a scientific point of view (Attai et al., 2016). Fifth, focusing on establishing *conversations* with stakeholders rather than disseminating organizational information (Lim, 2016). Sixth, respecting *patients' emotions* and reactions (De Vries et al., 2018). Seventh, integrating the organization's *corporate values* in each communication initiative (Zerfass & Viertmann, 2017). Eighth,

focusing on *long-term objectives* such as reputation or social engagement, rather than short-term initiatives (Yeob et al., 2017). Ninth, using *different formats* such as texts, images and videos to this way produce creative contents (Janz et al., 2016). And tenth, *monitoring* all communication actions and gathering information to adjust future communication plans (Pelitti, 2016).

Annual content plan. Defining an annual content plan constitutes the first step before implementing any initiative on social media platforms. This plan integrates patients association's brand architecture (identity, values, mission, vision, culture), twelve key messages that should be used for different campaigns, six main targets and four social platforms -Facebook, Twitter, Youtube and Website (See Table 7 below). All these elements should be defined and integrated between them before publishing anything on social media platforms.

Table 7. Annual Content Plan

Month	Brand Architecture	Key Message	Target	Platform
January	Identity	Emotional support for patients	*MT: Patients ST: Employees	Twitter, Youtube
February	Brand value 1	Innovation	MT: Media companies ST: Employees	Corporate Website, Youtube
March	Brand value 2	Ethics	MT: Public authorities ST: Hospitals	Corporate Website, Facebook
April	Mission	Patients' rights	MT: Hospitals ST: Employees	Facebook, Youtube
May	Vision	Patients' empowerment	MT: Donors ST: Shareholders	Corporate Website, Twitter
June	Culture	Excellence	MT: Employees ST: Volunteers	Facebook, Twitter
July	Identity	Medicine basic principles	MT: Hospitals ST: Public Authorities	Facebook, Youtube
August	Brand value 3	Patients' privacy	MT: Public authorities ST: Volunteers	Corporate Website, Facebook
September	Brand value 4	Human values	MT: Media companies ST: Donors	Corporate Website, Youtube
October	Mission	Health education	MT: patients ST: Volunteers	Twitter, Youtube
November	Vision	E-health	MT: Donors ST: Shareholders	Corporate Website, Twitter
December	Culture	Social engagement	MT: Employees ST: Volunteers	Facebook, Twitter

*Legend. MT (main target), ST (secondary target)

Source. Authors' elaboration.

Key Performance Indicators. These associations can use different indicators to evaluate how they are managing social media platforms. We propose to focus only on 5 indicators in each platform: *corporate website* (bounce rate, unique website visitors, average time on the page, top landing pages, and pages views per session); *Facebook* (number of fans, number of likes, post engagement rate, number of contents shared, and pages views by sources); *Twitter* (number of followers, number of impressions, average engagement rate, top 5 tweets by engagement, and hashtags performance); and *Youtube* (number of subscribers, total watch time, number of videos, video engagement and traffic source).

Using social media platforms for corporate communication purposes constitutes a true challenge for patients' associations. Our quantitative analysis shows that Spanish cancer patients' associations should improve their performance on these platforms. Many of these organizations do not have the economic and human means to manager online corporate communication initiatives in a professional way: recruiting journalists, outsourcing advertising agencies, investing in SEO and SEM campaigns, etc. That is why, CEOs and Board of Directors members in these associations need to understand the impact of these initiatives and take the management measures necessary for implementing a professional approach of corporate communication on social media platforms.

Despite all qualitative and quantitative inputs explained on this paper, we can highlight three main limitations. First, we did not have access to these associations' corporate communication strategies, so we could not explain why they take some decisions concerning social media platforms (communication objectives, main targets, number of platforms used, budget for online campaigns, or number of employees in their communication department). Second, we did not find any paper focused on this topic, which avoid us to compare our results. And finally, we could not contact patients to evaluate their perceptions about these associations' social media platforms. On the other hand, we recommend researchers interested in this topic to develop some areas during next years, such as how to train patients on corporate communication initiatives, how to integrate social media and mobile apps into these organizations' internal protocols, and how to evaluate their brand value from an economic point of view.

6. Conclusion

Social media platforms have become a true corporate communication for patients' associations. This paper aimed to analyze how Spanish cancer patients' associations managed their corporate website, as well as *Facebook*, *Twitter* and *Youtube*, for implementing communication initiatives allowing them to reinforce their brand and reputation. Based on our quantitative results, we propose three main conclusions. First, most Spanish cancer patients' associations use social media platforms for disseminating organizational and medical information, but not brand related elements such as their identity, values, mission, vision or culture. Second, the lack of quality content on some social media platforms, especially on *Youtube*, show that many associations do not have enough means (employees, budget, knowledge) to produce content for these platforms. And third, these associations should evolve from their current journalistic approach to a corporate communication one focused on intangible elements such as the brand, reputation, engagement and stakeholders' perceptions.

Based on these three conclusions, we propose three managerial recommendations to Spanish cancer patients' associations: a) focus on fundraising initiatives allowing them to obtain the budget necessary for recruiting experts in social media platforms, corporate communication and public health; b) prioritize health education initiatives to this way become a credible source of scientific information for both patients and health professionals; and c) implement a custom research management program allowing them to interpret the information gathered on social media platforms and this way adapt their online communication strategies to stakeholders' needs in terms of information.

7. Specific contributions of each author

Contributions	Authors' number
Research design	Author 1
Documentary search	Author 1
Data collection	Author 3
Critical data analysis and interpretation	Author 2 and Author 3
Review and approval of versions	Author 1 and Author 2

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Annex 1: List of Cancer Patients Associations

01. Asociación de Apoyo a la Persona Dependiente y su Entorno
02. Asociación Española de Adolescentes y Adultos Jóvenes con Cáncer
03. Asociación Antequera por Las Mujeres Mastectomizadas
04. Asociación Caudetana de Lucha Contra el Cáncer
05. Asociación Contra el Cáncer Municipios Área Cuenca Minera
06. Asociación Canaria de Donantes de Médula
07. Asociación Contra el Cáncer Gástrico y Gastrectomizados
08. Asociación Canaria De Cáncer De Mama y Ginecológico
09. Asociación Costuras en la Piel en Apoyo a Investigación del Cáncer
10. Asociación de Familiares y Afectados de Cáncer de Iniesta
11. Asociación Adelante
12. Asociación para la Donación de Médula Ósea y Cordón Umbilical de Extremadura
13. Asociación de Personas con Linfedema en Aragón
14. Asociación Española de Afectados por Linfoma, Mieloma y Leucemia

15. Asociación Española de Afectados por Sarcoma
16. Asociación Española de Cáncer de Tiroides
17. Asociación Española de Estética Oncológica
18. Asociación Española de Enfermedades Urológicas y Litiasis
19. Asociación Española de Fisioterapia Oncológica
20. AELEMIC - Asociación Española de Enfermos de Leucemia Mieloide Crónica
21. Asociación Española de Policías Donantes de Médula Ósea
22. Asociación de Familias Afectadas por el Síndrome de Lynch
23. Asociación de Familiares y Enfermos de Torre Vieja
24. Asociación de Familias Oncohematológicas De Lanzarote
25. Agora Castalla
26. Asociación Jiennense de Cáncer de Mama
27. Alameda del Tormes
28. Asociación de Laringectomizados de la Región de Murcia «San Blas»
29. Asociación de Lucha Contra la Leucemia y Enfermedades de la Sangre de León
30. Asociación de Laringectomizados de Extremadura
31. Asociación Lucha y Sonríe Por la Vida de Pilas
32. Asociación de Mujeres Afectadas por Cáncer de Mama y Ginecológico de Albacete
33. Asociación Aragonesa de Cáncer Genital y de Mama
34. Asociación Madrileña de Afectados por Linfedema
35. Asociación de Cáncer de Mama de Tenerife
36. Asociación Melillense Contra El Cáncer
37. Asociación de Micropigmentación Estética, Paramédica y Oncológica
38. Asociación AMYCO Contra el Cáncer de Mama
39. Asociación Onubense de Cáncer de Mama «Santa Águeda»
40. Asociación Oncológica Extremeña
41. Asociación Pitiusa de Ayuda a Afectados de Cáncer
42. Asociación Comarcal De Personas Afectadas Por El Cáncer
43. Asociación Española de Pacientes de Cáncer de Cabeza y Cuello
44. Asociación de Personas Laringectomizadas de Huelva
45. Asociación de Apoyo a Familiares y Enfermos de Leucemia
46. APSATUR ARAGÓN
47. División de Tumores Raros
48. Asociació Ariadna
49. Asociación Regional Madrileña de Atención y Rehabilitación de Laringectomizados
50. Asociación de Afectados por Cáncer de Ovario
51. ASATE - Asociación de Afectados por Tumores Cerebrales en España
52. División de Cáncer de Mama y Ginecológico
53. Asociación Contra la Leucemia y Enfermedades de la Sangre
54. Asociación de Estética Integral Oncológica
55. Asociación Infantil Oncológica de Madrid

56. Asociación para la Lucha Contra la Leucemia de la Comunidad Valenciana
57. Asociación Canaria Salud y Sonrisas
58. Asociación Candela Riera
59. Asociación Marco Luna
60. Asociación Oncovida
61. Asociación Suport i Companyia
62. Asociación Vizcaína de Laringectomizados y Mutilados de la Voz
63. Asociación Gallega de Afectados por Trasplantes Medulares
64. Asociación de Pacientes y Familiares de Cáncer Renal
65. AVÍVATE- Asociación de Salud a Través del Ejercicio Físico y Ocio para Pacientes Oncológicos
66. Asociación de Yecla de Afectados de Cáncer
67. Asociación de Ayuda a Las Personas con Cáncer y Familiares de Ronda y Serranía
68. Asociación Zamorana de Ayuda Frente al Cáncer
69. Asociación De Mujeres con Cáncer
70. División Cáncer de Cabeza y Cuello España
71. División Cáncer de Hígado España
72. División Cáncer de Páncreas España
73. División Cáncer de Piel y Melanoma España
74. División Cáncer de Próstata España
75. División Cáncer de Pulmón España
76. División Cáncer de Riñón España
77. División Cáncer de Vejiga España
78. Dona Médula Aragón
79. Dones en Actiu
80. Asociación de Pacientes con Cáncer Colorrectal
81. Federación Española de Asociaciones de Linfedema
82. Asociación Frangil Contra la Leucemia
83. Fundación Carlos Garrido
84. Fundación Cris Contra el Cáncer
85. Fundación Mari Paz Jiménez Casado
86. Fundación Sandra Ibarra de Solidaridad Frente al Cáncer
87. Grupo de Expertos en Medicina Estética Oncológica
88. Grupo De Investigación En Actividad Física Y Salud
89. HYDROskin Oncology
90. Asociación de Apoyo a Personas Afectadas por el Cáncer
91. Asociación de Afectados por Neoplasias Mieloproliferativas
92. Asociación de Pacientes con Tumores Neuroendocrinos
93. Organización Nacional de Afectados por Hepatitis
94. PAUSOZ-PAUSO
95. Prevençió I Informació Càncer Molins
96. Asociación Oncohematológica

97. ROSAE
98. Asociación Escuela de Pacientes Oncológicos
99. Associació Comarcal D'ajuda en el Tractament del Càncer
100. Somos Unidos Por El Cáncer
101. Sonrisas Pelonas
102. Tú No Vas a Poder Conmigo
103. Asociación Unidos Contra el Cáncer de Toro y Su Alfoz
104. Asociación Un Sí por la Vida
105. Ver and Ser
106. Associació Viudecan Supervivientes de Cáncer
107. Yo me pido vida

Notes

1. More information about these associations available on: <http://www.gepac.es/nuestras-asociaciones/>. Document retrieved on 12th February 2021.

