

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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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. Digital innovations like artificial intelligence, robotics, virtual reality or blockchain offer new ways of delivering healthcare (Deloitte, 2019), such as the use of sensors to monitor patients' conditions (Lupton, 2013) or the development of devices to ease the lifestyle of chronically ill patients. Since the 2.0 disruption, individuals are increasingly utilising m-health apps, wearables, social media platforms, and similar, to manage both health and illness. 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). All these innovations, however, are generating big amounts of data that organizations still do not know how to use it to enhance healthcare (Coulter *et al*, 2014). In addition, this information also challenges both the way patients relate to their bodies and the procedures health professionals employ to interact with these physical figures (Lupton, 2013; Lupton, 2018a; Lupton and Maslen, 2017). 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).

This paper focuses on social media, one of the tools that could be the next revolution in the treatment and self-management of healthcare (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; Newhouse *et al*, 2018). 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 an online environment.

Simultaneously, using social media for health care has also associated risks. As Lupton (2012, 2013, 2018b) points out, the data collected in these spaces can be used as a new form of surveillance. Most of the platforms are developed by private companies where the information is used without the patient’s consent (Lupton, 2013, 2018a). Besides, the practices of support could also have negative effects, such as polarisation of opinions, the transfer of responsibilities of health care from doctors to patients, or the generation of negative emotions because of comparing the

personal experience with the situation of other individuals (Lupton, 2012; Newhouse *et al*, 2018). Nevertheless, it is clear that social media offers these patients new opportunities of empowerment for managing their health (Lupton, 2013; Merolli *et al*, 2013b). In their study about online support groups, Coulson and Shaw (2013, p. 1698) argue that these spaces work as *communal brains* where users 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).

Another theory that can be applied to the context of social media is 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). Regardless of the theoretical perspective used by institutions, online “groups/communities can offer a number of advantages [...] in terms of social support” (Wright, 2016b, p. 2). However, these connections are rarely discussed with reference to

this theory. According to previous studies, social support describes “the functional content of relationships” (House, cited in Heaney and Israel, 2002, p. 186), and 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 this regard, earlier research already validated emotional and appraisal support “in the context of social media websites” (Cha, cited in Deng and Liu, 2017, p. 100).

One important aspect of this theory is that 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. Nevertheless, 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 these online environments. 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 spaces like social media–: if the users of the network do not interact, the provision of support through these platforms cannot take place.

Paradoxically, 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 (Lupton, 2018b; 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”. Over the years, organisations were more focused in collecting data rather than discover what to do with it (Coulter *et al*, 2014). Moreover, other 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. Consequently, this type of behaviour increases the communication gap between patients and physicians in these spaces. 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 (Lupton, 2018b; Lupton and Maslen, 2017; 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).

[insert 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.

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).

[insert Figure 1]

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.

[insert Table 2]

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 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 informational, emotional 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).

[insert Table 3]

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. By one side, 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). Certainly, 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. Firstly, 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 sufferers 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). Thirdly, 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 health 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; Lavorigna *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 (Lupton and Maslen, 2017). 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 could take part in the conversation simultaneously.

Nevertheless, the introduction of these tools for the management of health must come necessarily with a revision of physicians' work routines (Lupton, 2018b). Both "practitioners and patients are faced with finding new ways [...] to interact with technologies" (Lupton and Maslen, 2017, p. 1566), since some digital health resources transform the body in an element where the senses (like the touch) are absent (Lupton, 2012; Lupton and Maslen, 2017). Besides, "health care professionals are still learning to understand their patients' interactions with the Internet" (Newhouse *et al*, 2018). In this regard, practitioners face two major challenges with the expansion of these innovations,

because they need to learn how to diagnose a patient relying only on data (in the case of using a m-health app) and to deal with online information during consultations with these individuals (in the case of face-to-face interactions). Consequently, if we want to use these practices to improve the delivery of health care, “a more coordinated approach is needed [...] to make better use of people’s reports on their experiences” (Coulter *et al*, 2014). As Tjora and Scambler (2009) point out, most of the studies that discuss how to incorporate digital health into day-to-day habits of hospitals only put the focus on the micro level interactions.

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 (Newhouse *et al*, 2018). 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 (Lupton, 2012; 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.

Certainly, 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.

However, digital health does not automatically lead to more efficient systems. As Tjora and Scambler (2009, p. 523) argue, hospitals are “negotiated orders” that function because of complex decision-making processes. If technological innovations are introduced without considering these particularities, the most probable thing is that they end up failing (Tjora and Scambler, 2009). In a similar vein, Lupton (2013, p. 260) also points out that most of the studies in the field of digital health assume “that more information will lead to better healthcare and economic efficiencies” without analysing the issue in depth. Against this background, the development and implementation of these platforms requires to be supervised by the different actors who take part of the healthcare system; and it also needs “to be explored at meso- and/or macro-levels, factoring in professional awareness” (Tjora and Scambler, 2009, p. 523). In other words, digital health solutions will only be

successfully implemented if organisations consider these processes of negotiation. In this vein, the results of this review are strengthened with the findings of Tjora and Scambler's study.

In the same vein, this research and the possible application of social support theory presents 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 (Lupton, 2012, 2013, 2018b). 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. In short, before implementing digital solutions in health care, future studies need to consider the particularities and complexities of professional practices as well. 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.

Conflict of interest

The authors declare that there is no conflict of interest.

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Table 1. Databases used for this review.

| Web of Science Core Collection: Citation Indexes |
|---|
| 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 Science & Humanities (CPCI-SSH) |
| Book Citation Index– Science (BKCI-S) |
| Book Citation Index– Social Sciences & Humanities (BKCI-SSH) |
| Emerging Sources Citation Index (ESCI) |

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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) |
| 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 | SMsocialnetwork.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) |

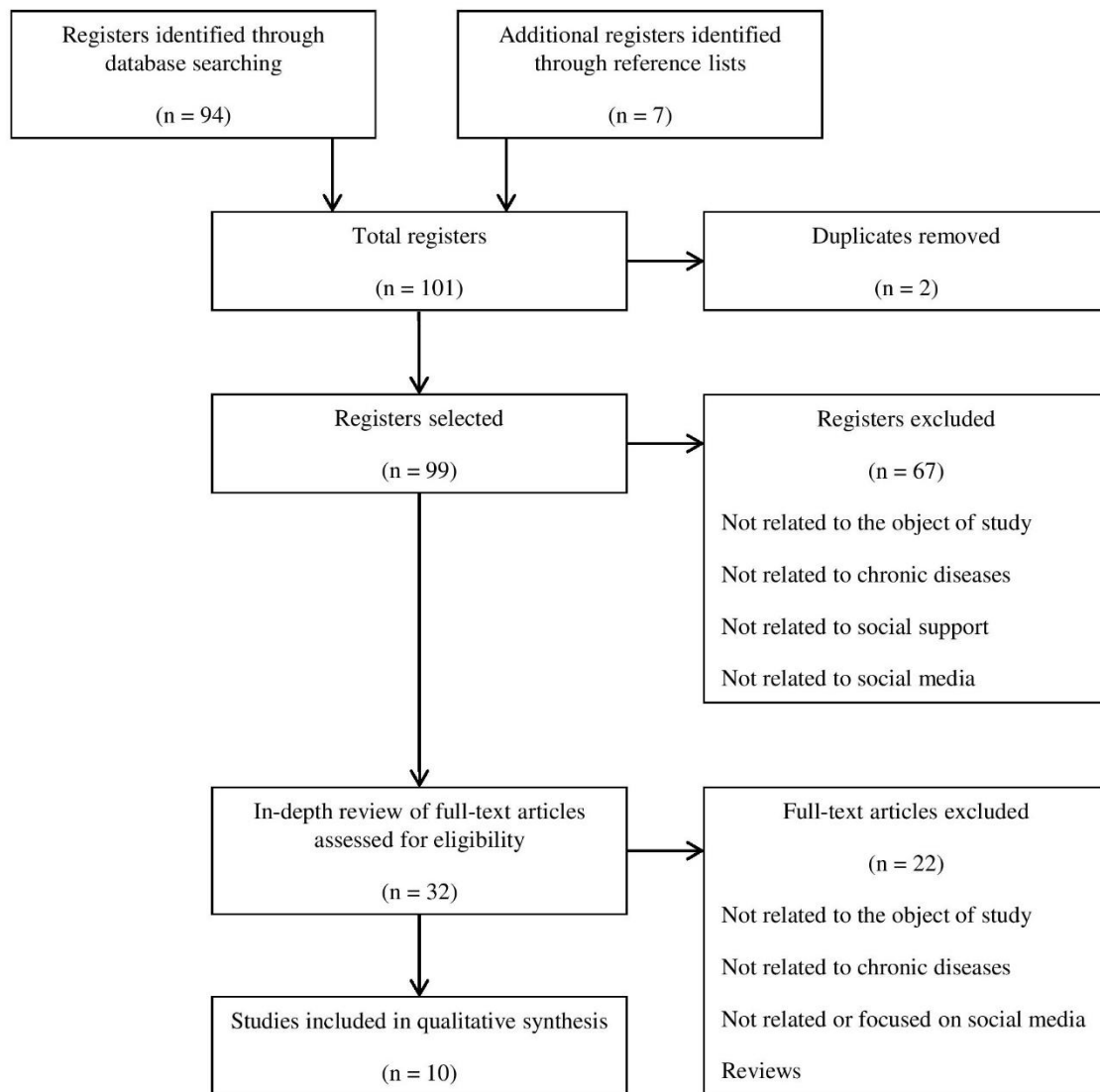
| | | | | | | | |
|---------------------------------------|--|--|--|--|---|--|---------------------|
| Magnezi et al. (2014) ³⁸ | Camoni | Multiple (diabetes, heart disease, spinal injury, kidney disease, depression/anxiety) | Examination of the effects and benefits of the participation in a health-based 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) |
| 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) |

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

| Author/s | 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 |

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



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