La participación de los pacientes con diabetes en grupos de apoyo online: implicaciones físicas y emocionales e impacto en la comunicación doctor-paciente

THE PARTICIPATION OF PATIENTS WITH DIABETES IN ONLINE SUPPORT GROUPS: PHYSICAL AND EMOTIONAL IMPLICATIONS, AND IMPACT ON THE DOCTOR-PATIENT COMMUNICATION

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Resumen

Los pacientes con diabetes sienten la necesidad de apoyo social, tanto emocional como informativo, que pueden encontrar en redes sociales y grupos de apoyo online. Este artículo adopta un enfoque comunicativo basado en una revisión de la literatura existente para tratar de abordar los problemas que dicha participación puede ocasionar en lo que respecta al bienestar físico y emocional de las personas que padecen diabetes.

Palabras clave

Redes sociales en línea, apoyo social, grupos de autoayuda, comunicación social, redes sociales
Abstract

Patients with diabetes feel the need for social support, both emotional and informational, which can be found in social networks and online support groups. This article takes a communicative approach based on a review of the existing literature to try and address the problems that said participation can cause in regards to the physical and emotional well-being of people suffering from diabetes.

Keywords

Online social networks, Social support, Self-help groups, Social communication, Social media.

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1. Introduction

Nowadays, people who suffer from a chronic illness (Fox, 2011) increasingly participate in digital communities (Bevan, 2017)- which include online support groups - in order to share their feelings, get emotional support and/or obtain information about their disease. Managing either type of diabetes requires an understanding of the disease, as well as emotional and informational support. In the case of patients with Type 1 Diabetes Mellitus (DM1), as a new source of learning; and for patients with Type 2 Diabetes Mellitus (DM2), as a source of updating or relearning information already acquired. Online support groups are forums where participants feel supported in cases of emotional distress, which increase as a result of the demanding self-care regimens and medical complications of diabetes mellitus. The so-called “stress-buffering model” explains how social support can provide the tools to manage disease self-care and even improve its condition (Ben-Sira, 1985; Peyrot & McMurry, 1992). According to this model, perceived social support weakens the negative perception of the stress suffered due to a chronic pathology and its impact on the patient’s health or quality of life. In the case of DM2, a study by Lee et al. showed the importance of informal health su-
Los participantes (familia, amigos) en el apoyo en línea dan al paciente la autonomía para enfrentar las rutinas diarias involucradas en el manejo del trastorno (Lee et al., 2018).

Este artículo es una contribución teórica que involucra una revisión de la literatura existente y se dirige a abordar, desde una perspectiva teórica, la relación entre la información que un individuo con diabetes puede encontrar en un grupo de apoyo online, las posibles consecuencias de consumir esta información, y el papel del profesional de la salud en el proceso de consumo de información y manejo del trastorno. El objetivo es clarificar la evidencia encontrada, ya que ha demostrado ser a menudo escasa y contradictoria. La propuesta es basada en la teoría de las redes sociales y enlaces, y aplicada a entornos online, con el fin de identificar los posibles efectos adversos de la comunicación entre redes sociales con el propósito de consumir información y sin mediación de ningún tipo. Posteriormente, se proporcionan herramientas conceptuales y teóricas desde una perspectiva comunicativa para optimizar los beneficios posibles de la comunicación doctor-paciente y la comunicación interpersonal en red social.

2. **framework teórico**

Los humanos tienen la necesidad de pertenecer a una comunidad y de seleccionar sus redes a través de la auto-selección, aunque existen otros factores psicológicos que pueden influir en sus decisiones (Christakis & Fowler, 2009). Por eso, se organizan en formas de comunidad, las cuales dan lugar a las redes sociales.

Una red social es una red de interacciones entre diferentes nodos. Los nodos representan a los actores y las aristas son los enlaces entre ellos (Aggarwal, 2011).

En entornos online, las fuerzas psicológicas y sociológicas involucradas en las redes sociales crean interdependencia entre los usuarios y promueven la formación de bandas de “herreros”, principalmente debido a nuestro biología evolutiva (que despierta nuestras ganas de pertenecer) y a nuestro sistema de selección de “herreros” (Baddeley, 2010).

Facebook es actualmente la red social online más activa, y conecta a más de 3,5 mil millones de personas (Hootsuite, 2019) dispuestas a crear contenido, colaborar y compartir sus conocimientos.

Los factores clave que afectan la difusión de un mensaje en una red social online son la homofilia y el influjo social (Bakshy et al., 2012). La homofilia es un fenómeno psicogénico basado en la similitud: la similitud anida conexión. Por tanto, los individuos tienden a asociarse con personas que son similares a ellos (McPherson et al., 2001). Por otro lado, definimos el influjo como el poder que alguien o algo tiene para afectar o cambiar a alguien o algo en un.
indirect but important way, with the aim to achieve a greater good for the group, team or organization (Wilson et al., 2016).

Because there are multiple factors that can affect an individual, different types of influence are taken into account (Scheer & Stern, 1992); social influence is the phenomenon that occurs when an individual’s behavior is likely to become assimilated into that of his or her social circle over time. The analysis of social influence in social networks is important at both the social and behavioral levels, as it can help to explain people’s behavior and decision-making process (Peng, Wang et al., 2017; Peng, Yang et al., 2017).

Patient support groups were first conceived in the 1980s to improve the quality of life of women with metastatic breast cancer through emotional support (Spiegel et al., 1994). These groups required the presence of a medical team (physicians, therapists, nurses), so they were expensive to implement. Today, these types of (offline) groups are not widespread, and are missing in the case of diabetes treatment. Online support groups, however, have been flourishing in recent years, as they combine the concept of a support group with the functionality of an online forum. Online forums are “groups of people with common interests and practices who communicate regularly and over a period of time in an organized manner on the Internet with a common location or mechanism” (Ridings et al., 2002). Online forums are characterized by 24/7 ubiquitous availability, anonymity, selective disclosure, and social networking (White & Dorman, 2001).

Online social groups function in a very particular way. Typically, a user’s first experience in discussing or contemplating the community’s knowledge is to respond to or interact with another user’s post (Landqvist, 2016). Therefore, the core activity of these groups revolves around sharing opinions and personal experiences, as well as selecting and distributing information to meet the needs of each author. Discussion threads in online forums can be viewed as a form of group communication, as they have the same characteristics as offline (face-to-face) support groups: namely size, interdependence, task, identity, and norms (Gritsenko, 2016).

Some popular online sites such as Facebook or Twitter have become community spaces where people with a chronic disease, such as diabetes, can interact with each other in a similar way as they would in a forum (Zhu et al., 2015). With an average of 1.59 billion daily users (Facebook, 2019), Facebook (FB) is currently one of the most popular sites among the population. FB allows for the quick and easy organization and management of public, private or secret groups. These revolve around any topic that the users, who created them in the first place, may be interested in, including diabetes. In order to join a private group, a user must be invited by a current member of the group (Facebook, 2021).
Research confirms that online forums and FB groups created for the purpose of discussing health-related topics are very similar: they allow participants to share their ideas in a post on which other members are able to respond, as if it were a thread in a forum. In addition, both FB and online forums allow the exchange of private messages between users. In general, FB groups and health-related online forums are thriving and provide support to their users (Nieuwboer et al., 2013). This support can be of different types, specifically in terms of confirmation, information, advice, and empathy (Carlsson et al., 2016). In general, health-related online support groups can be used to fulfill the need for information - which is strongly related with being able to ask specific questions -, or to obtain emotional support - which consists of sharing opinions and providing support to others (Reifegerste et al., 2017; Rains & Keating, 2015; Howard et al., 2001).

Therefore, given that people create stronger bonds with individuals who are similar to them (Christakis & Fowler, 2009a), it is assumed, based on the existing literature, that the opinion of a user in an online diabetes support group could have a bearing on the behavior or decision-making process of other users exposed to their message. This would mean that the way one person views a specific problem could alter the way another person does, affecting their emotional and/or physical well-being.

3. Methodology

3.1. Literature search

A search of the electronic databases Google Scholar, MEDLINE and PubMed, was undertaken in November and December 2020, using the search terms “social support” AND “diabetes” in the title and the abstract, AND (“support group” OR “informational support” OR “emotional support” OR “implications”) in full text.

3.2. Inclusion criteria

Our inclusion criterion was articles reporting an approach to the effect of informational and/or emotional support in patients with diabetes. For practical reasons, only articles written in English were retained. No restriction was used concerning the publication date. References from relevant studies were also examined to find additional titles.
3.3. Exclusion criteria

The exclusion criteria for this study were: studies involving a population under 18 years of age, studies not addressing support, studies with animals, studies not addressing chronical diseases and studies on sexually transmitted diseases. Studies of protocols that did not present partial results or qualitative results of reported interventions were also excluded.

When applying the above search procedure, and after elimination of duplicate articles, a total of 273 articles were identified. 31 articles met the inclusion criteria and were selected for further analysis. Of these, 16 were excluded. Finally, 14 studies were included in the qualitative synthesis. 7 were literature reviews or theoretical articles, and 7 concerned empirical studies. The search process is summarized in the flow chart shown in Fig. 1.

Figura 1. PRISMA Flow Chart.
4. Results

57% of the studies (8/14) were published from 2017. All the studies were published in English. This review includes 7 empirical studies (including one randomized controlled clinical trial), and 7 theoretical studies.

All patients in the intervention groups of the empirical studies were adults over 18 years. All of them except the ones in the study by Jacks & Thon (2017) reported to have been diagnosed with diabetes. Most of the studies did not specify the type of diabetes of the participants.

The number of participants ranged from 22 to 2419 participants. A wide variety of techniques and tools were used including: cross-sectional surveys and questionnaires, online experiments, online applications, pamphlets, peer supporters, integrative group, analysis of laboratory data, positive reinforcement, and focus groups.

Due to the differences in their methodology and sample, it is difficult to compare the findings of these studies and further investigations are needed.

Table 1 shows the summary of these studies, their methodology and sample, as well as the main findings related to this study.

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Methodology</th>
<th>Sample</th>
<th>Main findings related to the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thorne &amp; Paterson</td>
<td>2001</td>
<td>Qualitative approach and comparative methods</td>
<td>22 Canadian adults with T1D</td>
<td>Medical support is good because of medical knowledge, but also bad because it can lead to a feeling of control loss over the condition</td>
</tr>
<tr>
<td>Gomes et al</td>
<td>2017</td>
<td>Randomized controlled clinical trial</td>
<td>164 patients with T2D and over 40 years old</td>
<td>Patients improve when family members are incorporated into the care of the patient</td>
</tr>
<tr>
<td>Joensen et al</td>
<td>2016</td>
<td>Cross-sectional survey</td>
<td>2419 Danish adults with T1D</td>
<td>People with diabetes who establish good social relationships have fewer psychosocial problems</td>
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<tr>
<td>Author</td>
<td>Year</td>
<td>Methodology</td>
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<td>Main findings related to the study</td>
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<tr>
<td>Fan et al</td>
<td>2006</td>
<td>Questionnaire and laboratory data</td>
<td>1142 American adults with diabetes</td>
<td>Social support helps reducing the patient's psychosocial problems</td>
</tr>
<tr>
<td>Pimouguet et al</td>
<td>2011</td>
<td>Literature review</td>
<td>41 randomized controlled trials involving adults with type 1 or 2 diabetes</td>
<td>Social and emotional support have a positive impact on the blood glucose levels of patients with diabetes</td>
</tr>
<tr>
<td>Clark</td>
<td>2008</td>
<td>Literature review</td>
<td>11 systematic reviews and appraisals</td>
<td></td>
</tr>
<tr>
<td>Herrero et al</td>
<td>2019</td>
<td>Cross-sectional survey</td>
<td>307 Spanish adults with any type of diabetes</td>
<td>Belonging to these support groups has a positive influence on the perceived social support and motivation of people with diabetes</td>
</tr>
<tr>
<td>Jucks &amp; Thon</td>
<td>2017</td>
<td>Online experiment</td>
<td>78 German adults</td>
<td>The source of information lacks experience but it gains credibility through social validation, with a lack of criticism</td>
</tr>
<tr>
<td>Weitzman et al</td>
<td>2011</td>
<td>Observational study</td>
<td>11 social networks related to diabetes</td>
<td>Most of the information shared lacks medical accountability</td>
</tr>
<tr>
<td>Lazer et al</td>
<td>2018</td>
<td>Literature review</td>
<td>15 relevant scientific sources and papers</td>
<td>Information shared in OSG is not clinically proven</td>
</tr>
<tr>
<td>Campan et al</td>
<td>2017</td>
<td>Literature review</td>
<td>24 relevant scientific sources and papers</td>
<td>Information shared in OSG can be false</td>
</tr>
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### Table

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<thead>
<tr>
<th>Author</th>
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<th>Methodology</th>
<th>Sample</th>
<th>Main findings related to the study</th>
</tr>
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<tbody>
<tr>
<td>Waszak et al</td>
<td>2018</td>
<td>Social Media analysis</td>
<td>80 of the most frequently shared pages were re-viewed (top 10 in each keyword category)</td>
<td>Fake news in digital media may pose a potential threat to public health</td>
</tr>
<tr>
<td>Eysenbach &amp; Jadad</td>
<td>2001</td>
<td>Literature review</td>
<td>45 relevant scientific sources and papers</td>
<td>Not all users of digital media are able to understand what they read</td>
</tr>
<tr>
<td>Herrero et al</td>
<td>2021</td>
<td>Cross-sectional survey</td>
<td>307 Spanish adults with any type of diabetes</td>
<td>Participation in online support groups is correlated with poorer health and an increased appearance of complications arising as a consequence of suffering from diabetes</td>
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### 4.1. Social support for patients with diabetes

The diagnosis of diabetes involves a series of changes in the patient's habits: dietary restrictions, daily intake of new medication such as metformin, monitoring of blood glucose levels, insulin injections, and even the possible appearance of complications (nephropathy, retinopathy, cardiovascular problems, obesity or amputations) (Members et al., 2013). All of these changes help to explain the onset of distress (Polonsky et al., 2005), which is also related to poor diabetes self-management regimens (Pintaudi et al., 2015), and has an impact on the increased risk of complications in blood glucose levels, and on the mortality of the affected individual (Grigsby et al., 2002; Anderson et al., 2001; Nicolucci et al., 2013).

When this occurs, people with diabetes need social support to feel better. Although social support has different dimensions to it, the most common forms are informational support and emotional support (Roffeii et al., 2015; Loader et al., 2002; Eichhorn, 2008). Informational support refers to the exchange of relevant knowledge and information, whereas emotional support is based on the concern for others. Emotional support can also take place when users post their
personal experiences, as these encourage a more emotional response (Kimmerle et al., 2014).

In offline environments, patients with diabetes may find the first type of support at their physician’s office. This support is of particular relevance given that the medical professional's knowledge has the potential to improve the patient’s health, but it can also lead them to feeling a loss of control over their disease, giving way to confusion or even powerlessness (Thorne & Paterson, 2001). In addition, a large number of patients feel that a physician is not a good choice for emotional care because there is often a lack of empathy, an absence of trust on behalf of their patients, and very little capacity for communication and horizontal interaction (Leimeister & Krcmar, 2005).

The next common support system for a patient is their family. They turn to family with the goal of feeling more confident and empowered, as well as aiming to improve physical and emotional well-being (Taylor, 2017; Ford et al., 1998). Family members have also been shown to be helpful when they are incorporated into the care of people with diabetes (Gomes et al., 2017), but some patients lack this type of support and therefore may lack the motivation to manage their disease effectively.

When patients with a chronic disease do not find social support through their offline resources, they may develop a sense of alienation or isolation, increased anxiety about their treatment, and even believe misconceptions about it (McKenna et al., 1995). These patients may turn to social networks and online environments in order to find both informational and emotional support, although the latter is often the most sought after (Preece, 2000; Wright, 2002). Online forums and support groups also provide a pleasant environment in which to discuss how to solve diabetes-related problems; and this in turn leads to lowered stress (Costanza et al., 1988).

As several studies have shown, using the Internet to meet people may be associated with depression (Boneva et al., 2006). People with diabetes tend to be more depressed than people without diabetes (Holt et al., 2014; Mezuk et al., 2008), so this may be another reason why they seek out online forums and support groups.

A study carried out on obese adults (which is associated with diabetes) showed that forum activity is significantly correlated with perceived informational and emotional support (Reifegerste et al., 2017). The results of this same study also showed that women preferred support groups focused on emotional support, whereas men showed a predilection for informational support.

Those who participate in online forums or groups want to feel emotionally supported (Smithson et al., 2011); they are looking to give and receive the support they cannot find in offline environments. This is especially important because it means that patients may be turning to digital environments and accessing these
groups in order to find the emotional, or even informational support, that they are not finding with their physician or family.

The emotional benefits of diabetes-related online support groups could be significant, since the disease is increasingly prevalent worldwide (Wild et al., 2004; Chen et al., 2012; King et al., 1998) and is related, as we have seen, to other complications such as obesity, heart problems, nephropathy, neuropathy, or depression (Centers for Disease Control and Prevention, 2011; Rathmann et al., 2018). Furthermore, it seems that people with diabetes who establish good social relationships have fewer psychosocial problems (Joensen et al., 2016). Additionally, it seems that social and emotional support have a positive impact on the blood glucose levels of these patients (Fan et al., 2006; Pimouguet et al., 2011; Clark, 2008), thus becoming an important intangible asset that could have a positive impact on their lives, since optimal glycemic control can reduce mortality and the risk of obesity due to the disease.

Several studies have analyzed the contents of online support groups, both forums and Facebook groups (Greene et al., 2011; Al Mamun et al., 2015; Makoul et al., 2010), and another suggested that belonging to these support groups has a positive influence on the perceived social support and motivation of people with diabetes (Herrero et al., 2019).

However, although many users with diabetes may seek to participate in these online support groups exclusively for emotional support, the primary function of most groups is to provide instrumental support by becoming sources of information (Stellefson et al., 2019), since the user is interacting in a space where anyone can ask questions directly related to their health. Furthermore, even though users may be aware that the source of information lacks experience, because it is shared in an online support group it gains credibility through social validation (Jucks & Thon, 2017): users reach a consensus through comments of agreement and an overall lack of criticism, regardless of the veracity of the information and the experience of the source.

Therefore, although many people with diabetes join these groups only for emotional support, these platforms can become a source of information; a place where patients can ask questions directly related to their condition, and where anyone else can answer those questions, regardless of their expertise.

4.2. The issues with information consumption in online support groups

People attribute credibility to a source through two mechanisms: they focus on the credibility of the information or the source, or on the social validation of said
information or source (Petty & Cacioppo, 1986; Weitzman et al., 2011). This means that many users may trust certain information only because it has been validated by many others, rather than checking its veracity.

The quality of information differs between different online support groups. A study by Weitzman et al. (2011) evidenced that, although the information shared may be aligned with what is recommended by the science of diabetes and clinical practice, most of it lacks medical accountability. At the internal level, a large number of these groups had a subjective moderation system, which offers limited protection against the possibility of consuming false or incorrect information. At the external level, outbound links were found to websites that had issues surrounding their communication – such as difficulty in understanding their privacy policies or an overall lack of transparency –, and which might include misinformation about the “cure” for diabetes.

Fake news is created and shared in this environment. Fake news is defined as “fabricated information that mimics news media content in form but not in organizational process or intent” (Lazer et al., 2018, p.1). It overlaps with other information disorders, such as misinformation (false information) and disinformation (false information that is deliberately disseminated with the goal to mislead people). In digital communities, it is already common to find this type of false information (Campan et al., 2017; Shu & Liu, 2019), including medical links with misinformation that may pose a potential threat to public health (Waszak et al., 2018). Fake news is a very wide subject and further studies should be needed in order to approach the existing relationship with social support and the implications in the patients’ well-being.

According to one study (Johnston et al., 2013), the more an individual participates in an online forum, the greater the amount of information available, especially when it comes to personal knowledge and experiences. This increases the trust and credibility attributed to the sources, making the information the individual accesses through these networks more meaningful to them. The fact that the information shared and consumed in online support groups is not 100% rigorous and accurate can be an obstacle to diabetes self-management and care.

Furthermore, we find that not all users of digital media are able to understand every single aspect related to their disease or treatment: people considered “functionally illiterate” have a worse health status, aggravated by the existence of a high volume of health information found online that is presented at a much higher reading level than that of the average population (Eysenbach & Jadad, 2001).

For all these reasons, participating in health-related online support groups can be problematic, especially in the case of diabetes care, as it involves severe dietary restrictions and self-care management routines (Rathmann et al., 2018). These routines may be negatively influenced by an online support group accor-
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ding to the following rationale. Instead of giving the autonomy and the ability to self-manage the disease according to the stress-buffering model mentioned above, online support groups can be used to obtain information about entrenched negative habits that are difficult to change.

5. Discussion

According to the existing literature, the participation of patients with diabetes in online support groups can have both a positive and negative effect on their physical and mental well-being. On one hand, there are correlations between this participation and certain positive aspects (such as a reduction in the patient’s psychosocial problems (Fan et al., 2006), an improvement in blood glucose levels (Fan et al., 2006; Pimouguet et al., 2011; Clark, 2008), or increased motivation (Herrero et al., 2019). On the other hand, this participation may also lead to the consumption of information that lacks transparency and medical liability (Weitzman et al., 2011), is not clinically proven (Lazer et al., 2018) or is even false (Campan et al., 2017). This situation can be aggravated in the case of functionally illiterate persons (Eysenbach & Jadad, 2001) and whose direct effects on users have not yet been studied. This participation could thus be correlated with poorer health and an increased appearance of complications arising as a consequence of suffering from diabetes (Herrero et al., 2021).

The studies mentioned above also show obvious discrepancies between the causality of these effects, basing themselves mainly on correlations rather than direct causes. Therefore, it is not known whether negative disease management leads to a specific use of online groups, or the other way around. More studies are necessary in order to establish the effects of communication in the physical and emotional well-being of patients with diabetes, including more quantitative and qualitative data, larger and more relevant samples and specific models and variables (such as type of diabetes).

In communication studies, an individual’s internal self-conscious inconsistencies have been theorized as cognitive dissonance (Festinger, 1957). According to this theory, the individual feels the need to alleviate distress caused by inconsistencies in beliefs, ideas, values, and behaviors. This theory refers, then, to the discomfort a person feels when holding on to two contradictory beliefs, attitudes, or behaviors that are inconsistent with one another. In the case of a person with diabetes, cognitive dissonance could occur, for example, when they consume foods high in sugar with no restraint, whilst knowing that this is a dangerous behavior for their health.
More recently, in the era of social networks, and in order to address this dissonance, the reinforcing spirals model (Slater, 2015) suggests that media is used selectively as a social reinforcement of pre-existing attitudes and beliefs through the individual who is exposed to the information that reaffirms them. Thus, this model theorizes about the development of social identities based on the information and attitudes of third parties that we encounter as users in digital media, and which can lead to a change in our habits and lifestyle. Therefore, it would be impossible to establish causality between online information consumption and diabetes management, since they would both become cause and consequence of each other, constantly feeding back into each other.

A physician’s skills when it comes to communication or developing interpersonal relationships include being well informed in order to provide a more accurate diagnosis, offering appropriate counseling, giving therapeutic instruction, and having the ability to effectively establish relationships with their patients (Duffy et al., 2004; van Zanten et al., 2007), with the aim of achieving patient satisfaction and well-being (Brédart et al., 2005; Brinkman et al., 2007; Henrdon et al., 2004).

However, despite the development of numerous guidelines for the management of diabetes, many patients with this condition do not get optimal results from their visit to the physician because the health care system focuses more on short-term, acute disease than chronic disease (Funnell & Anderson, 2004); and because, in reality, 95% of disease management takes place at home by the patients themselves, with no follow-up from a medical team, and often without having had the necessary training to carry it out (Funnell & Anderson, 2000; Funnell & Anderson, 2002).

Personalized online information could be a way to foster the relationship between patients and their medical specialists. However, this requires constant training for both parties, which can be a barrier if, for example, patients do not have the resources to access such training, or health professionals suffer a deterioration in their communication, social and/or digital skills (Ha & Longnecker, 2010). These barriers could lead to a reduced number of visits to the physician’s office if the patient doesn’t feel comfortable with them, which could result in the patient turning instead to the Internet and to social networks to satisfy their informational and emotional needs, thus finding themselves increasingly distanced from proper medical supervision (Andreassen et al., 2006).

In these online settings, the patient becomes an active participant and is placed back at the heart of decision-making in regards to their health. This, however, does not necessarily mean that the decision taken is then communicated or shared with the healthcare professional, who is still positioned as the provider of legitimate knowledge about their disease (Swan, 2012; Lupton, 2013).
In this context, physicians must adapt to digital channels since they are preferred by their patients. Many health professionals already use digital channels such as e-mail to communicate with these patients (Santana et al., 2010), but there is still the need for a bigger investment in public education and awareness programmes that highlight the use of digital channels between physician and patient (Haluza et al., 2017), since current services and educational programs have not proven to be sufficiently appropriate for patients with diabetes (Pal et al., 2018).

Furthermore, the role of the physician when it comes to identifying and debunking fake news is essential so that this information does not pose a threat to public health (Waszak et al., 2018) or to the patients themselves, who may refuse to follow the specialist’s prescription based on information found online (O’Connor & Murphy, 2020).

There is, then, a problem in managing online communication and resources more effectively, both on behalf of patients with diabetes and medical professionals. Medical professionals should be aware of the major health-related fake news and information dangers and be aware of the consequences of online information consumption by people with diabetes and especially by those suffering from distress or other physical or emotional complications due to the disease.

This communicative approach could explain both the discrepancies observed in the different studies and the possible causality in the consequences produced by online support group activity. Further experimental research is needed to support or refute this hypothesis.

6. Conclusions

The various studies consulted for this article show the existing relationship between participating in online support groups and other aspects of the lives of patients with diabetes, at an emotional level and regarding the state of their health.

It is evident that, despite the fact that we live in a totally digital era, and that the online world is a part of our lives, this reality is not reflected or contemplated in medical practice. While instrumental support is offered, the same does not occur with the emotional or informational support that patients require. Since this need is not being met at the physician’s office, it is sought out in digital environments.

As several studies point out (Preece, 2000; Wright, 2002), patients with unmet emotional support needs are more likely to resort to online support groups. This can lead to the subsequent consumption of false information that in turn can arouse the need to resort to an informational support source that should have been covered by the specialist’s office, thus giving rise to behaviors that are detrimental to the patient.
The existing literature shows that new technologies can improve the lives of people with diabetes and their relationship with their specialist. However, most studies focus on how to improve the ease of digital communication between patient and doctor (Weiner, 2012), which can only occur if both the patient and the doctor have the knowledge, ability and willingness to use these channels - which are usually used for more bureaucratic affairs, such as requesting an appointment or a prescription (Lo & Parham, 2010). With the advent of online social networks, there has been a shift from the traditional, vertical doctor-patient communication model to a much more horizontal one in which patients are agents in the management of their disease and are empowered by the information and relationships they find online. The relationship between patients, digital media and how a specialist can help them consume the information they find there in an optimal way still requires further research.

If we want people, and specifically patients with diabetes, to have access to factual and safe health-related information, we should promote the use of digital media and the participation of medical professionals in the groups in which their patients are active, with the aim of preventing possible negative consequences for them. Conceivably, online forums and support groups should be managed and/or moderated by medical professionals who ensure the well-being of the community by guaranteeing the information shared therein is of greater quality.

Furthermore, patients’ communication needs should be taken into account in order to manage the communication strategy and the resources needed to implement it effectively and appropriately for each patient. This requires taking into account the patient’s attitude (including their motivation or need for informational or emotional support), their intellectual level and their difficulty in understanding the information conveyed (backing it up with brochures and guides), the volume of information conveyed and the timing (at the time of diagnosis, 6 months later, etc.), as well as the communication channel needed at each step along the way (direct personal communication, phone services, email follow-up, offline/online support group meetings, etc.). This strategic management of doctor-patient communication should be based on both existing evidence and future research.

Future analyses should study whether the education of people with diabetes in regards to the digital environment and the consumption of information should be in the hands of their specialist (endocrinologist, nutritionist, dietician, neurologist...), digital media and communication experts, or at their own risk.

This education could lead to the development of critical thinking in patients, helping them to consume information online in a way that is safer for their health and emotional well-being.
7. References


La participación de los pacientes con diabetes en grupos de apoyo online: ...


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