Do online support groups influence the well-being of patients with diabetes?

Noelia Herrero; Lluís Mas-Manchón; Frederic Guerrero-Solé

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Noelia Herrero Antonio https://orcid.org/0000-0002-7453-4772

Universitat Pompeu Fabra Roc Boronat, 138. 08018 Barcelona, Spain noelia.herrero@alum.upf.edu



Lluís Mas-Manchón

https://orcid.org/0000-0001-7446-7162

Universitat Pompeu Fabra Roc Boronat, 138. 08018 Barcelona, Spain Iluis.mas@upf.edu



Frederic Guerrero-Solé

https://orcid.org/0000-0001-8145-8707

Universitat Pompeu Fabra Roc Boronat, 138. 08018 Barcelona, Spain frederic.guerrero@upf.edu

Abstract

Diabetes is one of the most challenging long-term diseases (LTD) nowadays. Diabetes is associated with dietary restrictions, medical treatments and a strict life style, and has important emotional implications. The aim of this study is to analyze the impact of participating in online support groups (OSG) and participants' emotional well-being, social support, self-esteem and motivation. An online survey was disseminated in online forums about diabetes, in Spanish (N = 344). Results show that participating in OSGs has a significant influence on the four variables analyzed. However, the direction of this influence depends on participants' type of diabetes. Participating in OSG is associated with an increase in self-reported social support and motivation for type 2 patients with diabetes, while it is associated with a decrease of both variables for type 1 patients. No differences were observed for emotional well-being and self-esteem. These results have direct implications for both people with type 1 and 2 diabetes and medical professionals in managing online communications more effectively.

Keywords

Diabetes; Online forums; Media effects; Social influence; Emotional well-being; Self-esteem; Social support; Motivation.

1. Introduction

Diabetes is one of the most challenging long term diseases (LTD) of our age (**Zimmet**, 2011). The number of diabetes patients keeps increasing worldwide (**Wild** *et al.*, 2004). Diabetes is associated with dietary restrictions (regarding sugar or carbohydrates intakes), daily intake of new medication (like metformin), glucose monitoring, insulin injections, and a wide range of health problems and long-term damage (e.g., nephropathy, retinopathy, neuropathy, cardiovascular problems, obesity or amputations) (**Rathmann** *et al.*, 2018). The overall restrictions, medication treatment and eventual problems sometimes lead to poor diabetes self-management behaviors (**Pintaudi** *et al.*, 2015) and risks associated with overall health and depression (**Anderson** *et al.*, 2001; **Grigsby** *et al.*, 2002; **Nicolucci** *et al.*, 2013; **Holt** *et al.*, 2014).

Diabetes patients are likely to require informational and emotional support. Remarkably, some doctors frame the disease exclusively from a medical standpoint, thus making the patient feel confused or powerless since he or she does not own control on the condition (**Thorne**; **Paterson**, 2001). In addition, most patients believe the Most patients believe the doctor is not a good option for emotional care because they often lack empathy, trust and a more horizontal interaction

doctor is not a good option for emotional care because they often lack empathy, trust and a more horizontal interaction (Leimeister; Krcmar, 2005). Although family can give this emotional support and thus enhance the physical and emotional well-being of the diabetic (Ford; Tilley; McDonald, 1998), patients may also benefit from sympathizing with other patients by sharing personal experiences (Kimmerle; Bientzle; Cress, 2014). For this purpose, social media and online settings can be a particularly suitable sphere (Wright, 2002), and a proper use of those may contribute to solve problems related to diabetes and reduce stress (Costanza; Derlega; Winstead, 1988). Conversely, a high emotional burden is associated to a worse diabetes management (Joensen; Almdal; Willaing, 2016). This study aims to find the relations between the participation in an online forum or online support group and the emotional well-being of people with diabetes.

Online support groups (OSGs) increasingly assemble users worldwide, particularly those who suffer from an LTD. Diabetes patients participate in digital communities to share feelings and behaviors related to the disease (**Balkhi** *et al.*, 2014). Online support groups are a suitable platform for such a personal use because they are easily available, anonymous, and allow selective disclosure and social networking (**White**; **Dorman**, 2001). Besides, human beings have a natural inclination to form communities through social networking (**Baddeley**, 2010). This evolutionary trend has important psychological and social benefits (**Christakis**; **Fowler**, 2009).

In general, social bounds and communication are associated with greater emotional stability, lower levels of stress and motivation (Joensen; Almdal; Willaing, 2016; Baumeister; Leary, 2017). Social and emotional bounds can positively affect glucose levels and diabetes self-education (Clark, 2008). This is of great relevance because an improved glycemic control can reduce mortality and obesity from this condition. A study performed to adults with obesity (which is a side effect of diabetes) showed that forum activity is significantly correlated with perceived informational and emotional support. Findings in this study also revealed that females preferred support groups that focused on emotional support, while males preferred those focused on giving information (Reifegerste; Wasgien; Hagen, 2017).

Support groups were first conceived to improve life quality of women with metastatic breast cancer in the 1980's (**Spiegel** *et al.*, 1989). This kind of support group required the presence of a medical team at a cost that many patients could not afford. Online forums are

"groups of people with common interests and practices that communicate regularly and for some duration in an organized way over the Internet through a common location or mechanism" (Ridings; Gefen; Arinze, 2002, p. 273).

Online support groups are then the combination of support groups and online forums.

Users may participate in online support groups for several reasons, such as to share knowledge in order to show someone's concern for other users, to create a smaller and more homogenous community, or to meet with those that post comments –these comments are usually based on personal experience rather than in expert knowledge (Landqvist, 2016).

The key factors that affect a message's dissemination in online social networks are homophily and social influence (**Baks-hy** *et al.*, 2012). In essence, homophily refers to the users' trend to associate with users who resemble themselves; that is, people flock together with other people that are similar to them, and this breeds connection. Closely related to homophily, social influence is indirect ways of making someone behave or have attitudes in line with the group (**Wilson** *et al.*, 2016). For instance, a negative emotion towards improving some diabetic's glucose levels can be easily spread in social communities and have an influence on other people with diabetes.

With 1.49 billion daily active users on average, *Facebook* is the most popular social networking site (*Facebook*, 2018). *Facebook* allows the formation of groups of different size that allow people with similar interests to share information and express their opinion around a common cause. *Facebook* groups can be public, private or secret. Any user should be invited or accepted after a request in order to join a private group. These groups are very similar to an online forum as they allow participants to share their ideas in a post, and other members can answer this post as if it was a thread in a forum. Besides, both *Facebook* and online forums allow the exchange of private messages between users. In general, *Facebook* groups and online forums on health issues are thriving (**Nieuwboer; Fukkink; Hermanns**, 2013).

Aligned with the clear benefits of offline social bounds and communication, online interactions may also have social and emotional positive outcomes. However, a stream of research suggests that online interactions can lead to reduced we-II-being because it may lead people to spend more time online than offline, and be detrimental to real social interactions with strong ties like family and close friends (**Castellacci**; **Tveito**, 2018). Some studies even suggest that the use of the internet to meet people might also be associated with depression (**Boneva** *et al.*, 2006).

In essence, on the one hand, being diagnosed with diabetes has a significant emotional impact on the patient to the extent that people with diabetes show a higher prevalence of affective disorders like anxiety, depression and diabetes-related distress (**Polonsky** *et al.*, 2005; **Pintaudi** *et al.*, 2015; **Grigsby** *et al.*, 2002). On the other, participants enter online support groups (OSG) to obtain emotional support and information (**Smithson** *et al.*, 2011). Given this, to what extent do forums help diabetes patients to feel better emotionally? Some studies have analyzed contents in OSGs from both forums and *Facebook* groups (**Al-Mamun**; **Ibrahim**; **Turin**, 2015; **Costa-Sánchez**; **Míguez-González**, 2018; **Greene** *et al.*, 2011; **Makoul** *et al.*, 2010), but, to the best of our knowledge, none has tried to confirm if these support groups have an emotional affectation in patients with diabetes. Specifically,

RQ1: Does belonging to a diabetes online social group have an impact on individuals' emotional well-being, including social support, self-esteem, and motivation?

Overall, diabetes is a metabolic disorder characterized by chronic hyperglycemia. Physical and medical differences between diabetes type 1 and 2 are well-reported. Type 1 diabetes is usually called juvenile-onset diabetes (*International Diabetes Federation*, 2017) because it generally develops in childhood or adolescence. Due to the lack of beta cells in the pancreas, it is always treated with insulin (*World Health Organization*, 1999). This makes patients with type 1 diabetes to be accustomed to certain conditions from an early stage. On the contrary, type 2 diabetes is a common major form of diabetes in people over 40 years and therefore diagnosed when the patient already has a well-defined life style. Thus, the later has a natural impact on diet, habits and health care in general (*International Diabetes Federation*, 2017).

Very few studies have focused on the disease's management and emotional state of type 1 and 2 patients. **Lin** *et al.* (2017) found that glycemic control has a direct effect on diabetes self-management and indirect effects on depression and diabetes distress through diabetes self-efficacy and diabetes self-management in type 2 diabetes patients. Although depression is associated to both types of diabetes, recent studies have found that factors causing depression may be different for the two types (**Vučić-Lovrenčić**; **Pibernik-Okanović**, 2018).

In sum, although today's prevalence of obesity is affecting important segments of children population with type 2 diabetes (**Agrawal**; **Gensure**, 2018), type 2 diabetes patients tend to be an older and more heterogeneous segment than type I, with more hypoglycemia and hyperglycemia problems. A side effect of type 2 segment's sociodemographic and lifestyle characteristics is functional impairment and comorbidities –the confluence of different diseases, which may be reasonable to treat individually (**Chen** *et al.*, 2018). And recent research by **Wardian** *et al.* (2018) report that distress and emotional burden associated with diabetes treatments are higher for people with type 2 diabetes:

RQ2. Does the impact of belonging to a diabetes online social group on individuals' emotional well-being, including self-esteem, social support and motivation, depend on the individuals' type of diabetes?

2. Method and sample

A cross-sectional study using an online survey was conducted between May 19th to September 6th 2018. The study was approved by the ethical committee of the *UPF* university. The questionnaire was created in *Google Forms*. Participants were recruited online via a banner in *Dulces Diabéticos*'s website and through posts in both diabetes online forums and *Facebook* groups related to diabetes. Participants took as much time as needed in order to complete the survey (an average estimated time of 5 minutes). Only datasets with complete data were analysed. Two participants were excluded from data analyses because they did not provide their consent to participate in the study. 35 more participants were also excluded because they claimed not to have diabetes. The final sample contained 307 participants (mean age: 43,44; SD= 9,45; 49% men). Their academic degrees included Elementary school (8%), Secondary School (42%), Bachelor's Degree (39%), Master's Degree (7%), PhD studies (1%) or none (2%). 210 participants had Type 2 Diabetes (68% percent), 82 had Type 1 Diabetes (27%), and the rest reported having other types of diabetes.

The survey consisted of 4 parts. Firstly, participants were asked to answer questions related to diabetes and their behavior as patients, including the age of diagnosis and the medications being taken. Afterwards, the second set of questions referred to the use of the Internet, the belonging to online social groups and the reasons why they belonged to these groups.

68.1% were members of OSGs related to diabetes, while 39.1% were not.

Among those who were members of OSGs,

- 90.8% were members of a Facebook group,
- 41.5% of a diabetes-related forum,
- 3.9% of a health related forum and, finally,
- 1.4% were members of other online forums.

4.3% of them had been members of online forums for less than 6 months,

- 58.9% between 6 months and 3 years, and
- 36.7% for more than 3 years.

The third sets of questions refer to self-care. And, finally, the last set of questions refer to support-seeking (5 items, M=3.62; SD=0.64; Cronbach's alpha=0.66), perceived well-being (6 items, M=3.70; SD=0.75; Cronbach's alpha=0.83), self-esteem (7 items, M=3.90; SD=0.57; Cronbach's alpha=0.80), and motivation (3 items, M=3.94; SD=0.81; Cronbach's alpha=0.80), and motivation (3 items, M=3.94

alpha =0.86). Cronbach's alpha for the whole scale was equal to 0.78.

Users were targeted in a diabetes online forum (*Diabetes Foro*), *Dulces Diabeticos*' website and posts in several

Social and emotional bounds can positively affect glucose levels

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diabetes support groups among *Facebook* users. The posts were not addressed to anyone in special but specified that the study was addressed to people with diabetes, and therefore any person willing to participate could freely do it, anywhere, anytime.

https://www.diabetesforo.com https://www.dulcesdiabeticos.com

The independent variable, the online behavior of participants when engaging in social groups, was reported on a Likert scale ranging from 1 (daily) to 5 (never) following these statements:

- "the use of internet",
- "the use of social networking sites",
- "access to sites about health", and
- "comment or share information related to your health in SNS" (Giménez-Pérez et al., 2016; Suziedelyte, 2012).

Users were also asked whether they belonged or not to an online diabetes group and why (**Grande**; **Myers**; **Sutton**, 2006; **Kelly**; **Jenkinson**; **Ziebland**, 2013; **Stevens**; **Duttlinger**, 1998). Finally, some yes/no questions about health decisions were made (**Giménez-Pérez** *et al.*, 2016; **Kelly**; **Jenkinson**; **Ziebland**, 2013).

The dependent variables, encompassed within the variable well-being, were measured with 22 items presented in randomized order and rated on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Well-being as a variable (**McDowell**, 2006) includes other four dependent variables, namely:

- emotional well-being,
- social support (Cook-Cottone; Guyker, 2014; Grande; Myers; Sutton, 2006; Stevens; Duttlinger, 1998),
- motivation (Kelly; Jenkinson; Ziebland, 2013), and
- self-esteem (Lyubomirsky; Lepper, 1999; McDowell, 2006; Rosenberg, 1965).

First, emotional well-being is the emotional quality of an individual's everyday experience, which includes the frequency and intensity of experiences of joy, sadness, anger, stress, and affection that make someone's life pleasant or unpleasant (**Kahneman**; **Deaton**, 2010), and is measured with statements such as

- "In general, I feel good physically and mentally",
- "In the last month I have been nervous",
- "I feel that I have full control over my behavior, thoughts, emotions, or feelings", or
- "During the last month, I have felt depressed"

adapted from Dupuy (1978) and Fazio (1977).

Second, social support refers to information leading one to believe that he or she is cared for, esteemed, loved, and a member of a social network of mutual obligations (**Cobb**, 1976), adapted from *Mindful Self-care Scale* (**Cook-Cottone**, 2016) and two items from **Carpenter** (2012), –namely seek and provide support to others-, and includes statements such as

- "I am a person who seeks support in others",
- "I am a person who offers support to others",
- "I feel supported by my relatives" or
- "I feel supported by my friends".

Third, motivation is an equivalent term to determination and refers to emotions and motives being able to determine or influence someone's behavior regarding his or her health condition (**McClelland**, 1987; **Kelly**; **Jenkinson**; **Ziebland**, 2013), and includes statements such as

- "I have been feeling sad in the last month",
- "I learn something new every day",
- "Every day I am more motivated to improve my illness",
- "I feel that diabetes restricts my life",
- "I feel good physically and psychologically",

from the generic item pool to assess the effects of websites with experiential and factual health information validated in **Kelly** *et al.* (2013).

And forth, self-esteem (**Rosenberg**, 1965) is defined as a personality trait which refers to people's evaluations about their own worth, competence and desirability (**Konrath**, 2014), and includes statements such as

- "I am satisfied with myself",
- "I think I'm a worthwhile person" or
- "I think I have positive qualities".

3. Results

To answer to the first research question about the relationship between belonging to OSGs related to diabetes and emotional well-being, self-esteem and motivation we first performed a bivariate correlation test between these four variables. As it is shown in table 1, all the four variables are positively correlated, and all the correlations are statistically significant.

Afterwards, we performed an anova to test whe-

ther the belonging to OSGs (independent variable) had an impact on any of the four variables analyzed.

Since diabetes patients' behavior in OSGs may differ by type of diabetes, we split the sample in two: (1) patients with type 1 diabetes and (2) patients with type 2 diabetes. We then first calculated the anova values for the 4 variables with type of diabetes as the independent (Table 3).

As it is shown in table 3, the mean scores of support, we-II-being, self-esteem and motivation between type 1 and type 2 groups of patients are statistically different. Consequently, we performed the same anova tests for both types of diabetes, with belonging to OSG as the independent variable (tables 4 and 5).

Results in table 4 and 5 show that there are significant differences between both groups when it comes to the impact of belonging to an OSG or not. While in patients with type 2 diabetes belonging to OSGs significantly increase the scores of support and motivation, in patients with type 1 diabetes these scores significantly decrease for those two variables too. On the contrary, no changes are observed for well-being and self-esteem.

To confirm these results, four two-way anovas were conducted to examine the effect of type of diabetes and belonging to an OSG on social support, emotional well-beTable 1. Bivariate correlations between support, well-being, self-esteem and motivation

	1	2	3
Support (1)			
Well-being (2)	0.187**		
Self-esteem (3)	0.322**	0.655**	
Motivation (4)	0.568**	0.411**	0.663**

Table 2. Mean values for support, well-being, self-esteem and motivation (standard deviation in parenthesis), and anova for belonging/not belonging to OSG (N=304).

	Belongs to OSG		Difference	Fuelue	
	No	Yes	Difference	r value	p value
Support	3.50 (0.73)	3.70 (0.59)	0.20	6.006	0.015
Well-being	3.60 (0.90)	3.76 (0.66)	0.16	3.006	0.084
Self-esteem	3.90 (0.73)	3.91 (0.49)	0.01	0.036	0.850
Motivation	3.76 (0.89)	4.02 (0.76)	0.26	7.178	0.008

Table 3. Mean values for support, well-being, self-esteem and motivation (standard deviation in parenthesis), and anova for type of diabetes.

	Type of diabetes		D://	E I	
	1 (N=83)	2 (N=210)	Difference	r value	pvalue
Support	3.48 (0.85)	3.68 (0.54)	-0.20	5.237	0.023
Well-being	3.27 (1,00)	3.85 (0.54)	-0.58	40.405	0.000
Self-esteem	3.74 (0.74)	3.96 (0.46)	-0.22	8.729	0.003
Motivation	3.54 (1.05)	4.09 (0.65)	-0.55	28.952	0.000

Table 4. Mean values for support, well-being, self-esteem and motivation (standard deviation in parenthesis), and anova for belonging/not belonging to OSG for type 1 diabetes (N=83).

	Belongs to OSG		Difference	Evelue	
	No	Yes	Difference	r value	pvalue
Support	3.80 (0.64)	3.33 (0.92)	-0.47	5.772	0.019
Well-being	3.15 (1.01)	3.38 (0.99)	0.23	0.888	0.349
Self-esteem	3.79 (0.83)	3.71 (0.72)	-0.08	0.200	0.656
Motivation	3.85 (0.86)	3.35 (1.11)	-0.50	4.147	0.045

Table 5. Mean values for support, well-being, self-esteem and motivation (standard deviation in parenthesis), and anova for belonging/not belonging to OSG for type 2 diabetes (N=210).

Belongs to OSG		Difference	Evelue		
	No	Yes	Difference	r value	pvalue
Support	3.35 (0.76)	3.82 (0.34)	0.47	36.269	0.000
Well-being	3.78 (0.78)	3.89 (0.41)	0.11	1.660	0.199
Self-esteem	3.93 (0.67)	3.98 (0.35)	0.05	0.382	0.537
Motivation	3.70 (0.92)	4.26 (0.40)	0.56	36.706	0.000

ing, self-esteem and motivation. We found again a statistically significant interaction of the independent variables on support [F(1, 281) = 29.552, p=0.000] and motivation [F(1, 281) = 25.257, p=0.000], and no significant interaction for emotional well-being and self-esteem (Figure 1).



Figure 1. Plots of the estimated marginal means for the effect of belonging to OSG and type of diabetes on social support, emotional well-being, selfesteem and motivation.

4. Discussion

Our results show that belonging to OSG has a positive influence on social support and motivation experienced by people with diabetes. Having a direct connection between belonging to OSG and social support has a straightforward discussion: OSG foster social contact with other people with diabetes and this is a direct way of being supported. With regard to motivation and self-esteem, the former refers to the state of the individual with regard to the community or society whereas the latter is a more introspective variable that refer to the individual. OSG are used to build a community of people with diabetes but have no influence on the patient's assessment/concept of himself/herself.

Therefore, in line with previous research, support groups contribute to emotional stability, lower the levels of stress and increase motivation (**Joensen**; **Almdal**; **Willaing**, 2016; **Baumeister**; **Leary**, 2017). Arguably, this finding reinforces the emotional benefits of communicating and holding social bonds with peers. However, the fact that these social bonding and communication takes places online adds insights to this process. Particularly, the mechanisms of social influence and homophily are crucial in OSG and should be discussed as determinants of these findings.

However, our research found that there exist significant opposed differences between the two types of diabetes regarding social support and motivation.

While for people with Type 1 diabetes belonging to OSG has a negative impact on social support and motivation, the

impact for people with Type 2 diabetes is significantly positive, as it is the impact on self-esteem and emotional well-being. These findings reinforce all said for the type 2 diabetes patients, and puts the focus on the emotio-

Being diagnosed with diabetes has a significant emotional impact on the patient nal, social and individual benefits of OSG on people with type 2 diabetes. As pointed out, researchers are aware that types 1 and 2 have rather different impact on the physical and emotional condition of patients (**Wardian** *et al.*, 2018). Despite the lack of research on how the Belonging to OSG has a positive influence on social support and motivation experienced by people with diabetes

benefits of social bonds and communication may be specific to the types of diabetes, we found OSG to have stronger impact on the type 2 diabetic's well-being. Type 2 patients are expected to have more problems to deal with the disease, as they should accustom their lifestyle in general. In this line, some studies have already reported greater difficulties for managing the disease, depression and instability (Lin *et al.*, 2017; Wardian *et al.*, 2018).

Our findings point to clear differences in the social and emotional requirements of diabetes type 1 and 2. They rather seem different diseases or, at the least, with different emotional implications. There is a gap of knowledge to be filled here in forthcoming studies. Anyhow, results call for further research on the impact of OSG for people with type 1 and 2 diabetes, as the former are not clearly gaining benefits from it.

5. Conclusions

This study evidences the differences of the impact of belonging to OSG self-reported social support and motivation between people with type 1 and type 2 diabetes. OSG increases the means of both variables for type 2, and decreases them for type 1. No differences were observed for emotional well-being and self-esteem. These results may assist both diabetes patients and medical professionals in managing online communications and resources more effectively, in particular, when patients seek social support from others that are more experienced in the diabetes field.

This study is not without limitations. First, the quantitative nature of the study has important limitations, specifically the use of self-reported scales. Some qualitative approaches may help gain insights into the impact of online social groups. Second, the sample of type 1 and 2 participants is unequal (27% of the sample were type 1), probably because OSG are heterogeneous and type 1 represents less than 10% of people with diabetes (*International Diabetes Federation*, 2017). Further investigation should take this into account.

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