

How Do Online Communities of Patients Aggregate on Twitter?

An Affordance Perspective

Completed Research Paper

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Abstract

This paper seeks to explore the key affordances influencing patients' engagement with online communities on Twitter. Drawing on a socio-technical perspective of affordances, the paper presents the qualitative analysis of a sample of tweets from a patients' community chat on Twitter. The paper makes the following contributions. First, it draws on the concept of composite affordances to show the influence of affordance relationships on patients' engagement with online communities on Twitter. Second, it extends our knowledge about the implications of the attributes of Twitter digital objects for the realization of affordances that influence engagement in patients' online communities. The paper furthers our understanding of the main factors that influence aggregation and interaction within communities of patients on Twitter.

Keywords: online communities, healthcare, affordances, digital objects, Twitter

Introduction

The growth of Internet technology and Web 2.0 has seen an increase in the use of social media among patients. Social media platforms, such as Twitter, Facebook and patients' networking sites, have enabled the formation of patients online communities, whose members interact, communicate, and exchange information about their medical condition and treatment (Josefsson 2005). Some argue that patients' online communities have increased the opportunities for patient-centered care. On the one hand, patients can use social media to share their experiences with a medical condition and gain a better understanding of how they should manage their own health (Merolli et al. 2013; Troncone et al. 2015). In addition to better access to healthcare information, patients' engagement with online communities trigger a series of mechanisms, such as emotional support and patients' empowerment, which can have therapeutic effects (Johnson and Ambrose 2006; Leimeister et al. 2008; Merolli et al. 2014). On the other hand, traces of patients' data on social media sites can be used by healthcare organizations for health service improvement (Greaves et al. 2013), commercial and research purposes (Lupton 2014). Patients' networking sites such as Patients Like Me, for example, have been increasingly used in medical research to source health data (Kallinikos and Tempini 2014; Tempini 2015).

Patients' active participation and contribution to online communities are important to satisfy the emotional and information needs of their members (Zhao et al. 2015). In addition, by keeping users engaged, online communities can produce large quantities of data to be used in medical research (Tempini 2015). Therefore, it is important to understand the factors that influence patients' engagement with online communities. This study draws on the notion of affordances (Majchrzak and Markus 2013) for

a better understanding of users' interactions within online communities. Affordances of a digital platform are important because they attract and motivate users' participation on social media (Majchrzak et al. 2013).

Available studies provide a useful, but general overview of social media affordances and their implications for patients' well-being (Merolli et al. 2014). Little attention is paid to the role of social media affordances in influencing participation in online communities of patients. In addition, most research focuses on patients' online communities active on healthcare organizations' discussion boards and specialist networking sites (Kallinikos and Tempini 2014; Nambisan 2011; Zhao et al. 2013). Less is known about the activity of online communities on social networking sites (Troncone et al. 2015). This study contributes to research in this area by analyzing the activity of a diabetes online community on Twitter. More specifically, *the objective of this paper is to explore the key affordances influencing patients' engagement with online communities on Twitter.*

This paper pays attention to the "socio-technical" dimension of affordances (Robey et al. 2013), which are only in part determined by the technical features of a digital platform. In fact, affordances emerge from users' encounters with a technology and represent what users can do with them in relation to their goals (Markus and Silver 2008). Therefore, affordances need to be understood in relation to the technical properties of a technology together with the social dimension of users (Hultin and Mähring 2014; Zheng and Yu 2014).

In social networking sites like Patients Like Me, designers can manipulate the possibilities of action afforded by introducing new digital objects and data structures that guide patients' inputs and interactions (Tempini 2015). Social networks on Twitter are wider and more fluid compared to online communities on patients' networking sites where patients' experience with a disease constitutes a strong element of cohesion and participation (Kallinikos and Tempini 2014). There are limited functionalities mediating users' interactions (e.g. #hashtags, Re-Tweets, @username mentions) and their role in affording patients' interactions in online communities is not properly understood.

In order to achieve such an understanding, the paper will seek to answer the following questions: i) how do affordances and their relationships influence patients' engagement with online communities on Twitter?; ii) how do Twitter "digital objects" support the realization of affordances in online patients' communities? To answer the first question, the analysis of the relationships between affordances will be based on the concept of "composite affordances", which indicate how the realization of an affordance may rely on other affordances (Gaver 1991). The second question is addressed by drawing on the concept of digital objects and their attributes.

This paper is structured as follows. The next section discusses online communities of patients. This is followed by an illustration of composite affordances and digital objects and how these concepts will be used to understand the influence of Twitter on patients' engagement with an online community. The data collection and analysis methods are then discussed followed by results, discussion and conclusions.

Online Communities of Patients

Online communities are collectives of individuals who share common interests or concerns (Faraj et al. 2011). These communities are geographically dispersed and unaffected by temporal limitations (Johnson and Ambrose 2006; Zhao et al. 2013). At the same time, their members perceive them as cohesive groups of people they can relate with (Faraj et al. 2011; Zhao et al. 2013).

Members' contribution to an online community may be driven by their "sense of engagement" (Ray et al. 2014). Engagement concerns members' personal motivation to satisfy their community needs. Thus, contributing to a community is considered "socially important" and "personally meaningful" (Ray et al. 2014).

In patients' online communities the main drive to knowledge contribution is the sense of empathy that members perceive by sharing medical facts and information, personal experience and by providing mutual support (Zhao et al. 2013). The sense of empathy achieved through patients' participation to online communities can have a positive impact on patients' state of mind and well-being facilitating healing and recovery (Nambisan 2011).

Community identity, i.e., the identification with a group that shares common values, can raise members' perception of empathy (Zhao et al. 2013) and sense of engagement (Ray et al. 2014), thereby enhancing contribution to a community. A greater sense of empathy is also linked to trust, which members gain by behaving with integrity and conforming to community norms (Zhao et al. 2013).

Empathy is often associated to the social and emotional support that patients can receive from communities of patients that experience living with the same medical condition. They perceive greater empathy from these communities than from family members or friends (Nambisan 2011). Yet, not in all circumstances does community support lead to an increased sense of empathy. For example, Nambisan (2011) found that perceived empathy in the online community of a healthcare organization was influenced by access to experiential information rather than social support. She suggests that patients may perceive online communities run by healthcare organizations as a place to seek medical advice rather than support from their peers. This explains why support did not have a significant relationship with empathy. These findings imply that online communities may experience empathy, engagement and other factors influencing participants' contribution differently depending on the possibilities of action afforded in the digital platform that hosts them. In this regard, Nambisan (2011) suggests that social support is more likely to affect perceived empathy in online communities that are active on social networks such as Twitter. Users' interactions on social networks are governed by the "homophily principle" (Park et al. 2012). According to this principle, users are more likely to interact with people that are similar to themselves, share similar interests or ideas. Thus, social networks and the online communities that they support are more likely to experience homophily, which is also a predictor of perceived empathy (Nambisan 2011).

To conclude, users' engagement in online communities of patients is sustained by the social technologies that enable their interactions. It is the social element that attracts them to the network and constitutes an incentive for sharing their opinions about a healthcare service and their health status (Kallinikos and Tempini 2014; Merolli et al. 2013). Thus, affordances related to users' individualized and social needs are fundamental conditions whereby users engage with and share their experiences on social media. This study focuses on those affordances that are salient for patients' engagement with online communities on Twitter.

Affordances and Digital Objects

Composite Affordances

The notion of affordances dates back to Gibson's (1977) work in the field of ecological psychology to understand how an animal reacts to the properties of its environment. Gibson views affordances as possibilities of action available to an animal in a given environment. Researchers in the IS field have used the notion of affordances to understand the possibilities of action of a technology that are available to users (Goh et al. 2011; Majchrzak et al. 2013; Strong et al. 2014). They support a relational view of affordance whereby the realization of specific actions (or affordances) is linked to both the technical features of a technology and the ability of users to perceive and use them (Markus and Silver 2008). More recent studies stress the importance of the social environment in influencing users' perception and realization of affordances (Andersen 2011; Faraj et al. 2011; Robey et al. 2013; Zheng and Yu 2016). Thus, users may perceive the possibilities of actions available in a technology design as either constraining or enabling according to their social norms and beliefs.

In this study, the notion of technology affordances as sharing both a technical and social nature is important because it allows us to conceptualize patients communities on Twitter as patterns of social relationships entangled in the digital infrastructure of social media (Kallinikos and Tempini 2014; Tilson et al. 2010). This paper draws on Gaver's (1991) concept of "composite affordances" to better understand the pattern of online community relationships afforded in social media.

Gaver and, subsequently, other scholars in human-computer interface design, relate the complexity of actions to groups of affordances (Gaver 1991; McGrenere and Ho 2000). In this respect, Gaver (1991) proposes the definition of affordances as either "sequential in time or nested in space" (p. 82). Sequential affordances refer to the situation where the actualization of one affordance may lead to a new affordance. A common example of a sequential affordance in a word-processor is the actualization of "selecting text in

one document” by a user which leads to other possible actions (or affordances), such as “copying text in one document” or “cutting text in one document” that the user can realize. Nested affordances concern the realization of an affordance from the combination of other affordances. For example, “copying text from one document to another” relies on the affordances “copying text in one document” and “pasting text into another document”.

To date, there is little research about affordances of social media. An example is the study conducted by Merolli et al. (2013), who identify identity (or “self-presentation”), flexibility, structure, narration and adaptation as key affordances. Other studies confirm the existence of these affordances as shown in Table 1 below. By adopting the concept of composite affordances, this paper seeks to contribute to the dearth of studies in this area. In particular, it seeks to increase our understanding of how the patterns of relationships between different affordances affect patients’ engagement with online communities on Twitter.

Affordances	Description	Literature
Self-presentation	Users can choose and control what they want to disclose about their identity and their medical condition.	Merolli et al. (2013) – literature review and Merolli et al. 2014 – online survey Josefsson (2005)
Flexibility	Possibility of communication and interaction anytime, anywhere.	Merolli et al. 2013 – literature review
Connection	Extended possibilities for information sharing, collaboration, and social interaction help patients’ self-management and mitigate isolation.	Merolli et al. (2013) – literature review and Merolli et al. (2014) – online survey Kallinikos and Tempini (2014) Griffiths et al. (2014)
Narration	Value of shared experiences and the emotionally cathartic role they play.	Merolli et al. 2013 – literature review and Merolli et al. 2014 online survey Troncone et al. (2015) Josefsson (2005)
Adaptation	Possibility to access information and support that best suit changing needs of patients.	Merolli et al. (2013) – literature review
Exploration	Information seeking purpose.	Merolli et al. (2014) – online survey Troncone et al. (2015) Griffiths et al. (2014)

Table 1. Example of social media affordances

Digital Objects and their Attributes

Affordances of a technology are finite, depending on the number and type of design features of a system (Markus and Silver 2008). Digital system designers can seek to “pilot” the type of affordances that could possibly emerge from users’ interaction by manipulating the data structure or features of the system. For example, in his study about an online patients’ platform, Patients Like Me, Tempini (2015) demonstrates how designers can develop data structures that direct the input of patients towards a certain outcome by augmenting the specificity about a medical condition like arthritis.

Social media can amplify the effects of computer-mediated interaction and the social relationships that arise from such interactions. Taking Twitter as an example, by recombining the hashtag “#” with different strings of characters, users can collect different types of data and trigger unpredictable patterns of social

interactions and digital representations. In this way, social networks stimulate new forms of creativity through “the constrained serendipitous interactions” afforded in digital platforms (Yoo et al. 2012).

Not enough attention has been paid to the technical properties of social media in the realization of affordances (Spagnoletti et al. 2015). In this study, particular importance will be given to Twitter digital objects as generating the conditions for the possibilities of actions (or affordances) realized by online community members.

Digital objects include all digital technologies, devices and digital cultural artifact, such as music, video, and image. Digital objects have generic attributes, which determine their main functionalities (Kallinikos et al. 2010). A review of digital objects attributes is provided in Table 2 below.

Digital objects attributes	Description	Twitter	Literature
Editability	Digital objects are editable. They can be modified at any time. For example, you can modify, software libraries, digital repositories (blogs, wikis, booking systems etc.).	Tweets have limited editability. You can delete them but you cannot modify them.	Kallinikos et al. (2010).
Interactivity	Digital objects are interactive. Users can activate functions embedded in digital objects allowing for the exploration of different arrangements of information. One example of interactivity is given by hyperlinks in a web site.	Interactivity in tweets is limited to Re-tweets (RT) and QuoteRetweets. The only way to interact with a tweet is to replicate it.	Kallinikos et al. (2010); Val (2012).
Addressability	Digital objects can be uniquely identified in a computing architecture. Embedding RFID chips, barcodes, and microprocessors into digital artifacts makes them addressable.	A unique identifier in Twitter is @username.	Yoo (2010).
Traceability	By memorizing information collected from the environment, digital objects also become traceable, i.e., they can be traced in time and space.	#hashtags can be used to trace tweets.	Yoo (2010); Sharma (2013).
Associability	Associability refers to the possibility of associating information with actors, artifacts, places, and events. It is enabled by tags and keywords.	#hashtags can be used to create associations between topics, events, etc.	Yoo (2010).
Simplicity		A tweet characteristic due to its limit of 140 characters.	Dwyer and Fraser (2016).
Expansibility	The ease with which a “material bearer of an object” can be made available to potential users. Widespread diffusion of computers and Internet access and increased availability of storage space allow multiple users to download computer files.	#hashtags extend reach of messages beyond account’s network of followers.	Faulkner and Runde (2009); Dwyer and Fraser (2016).

Recombinability	Different digital objects or parts of the same digital object can be bundled together to produce something new (e.g. mashups).	Tweets can be combined with links, videos, and images.	Faulkner and Runde (2009); Val (2012).
Generativity	Digital objects can enable spontaneous change by uncoordinated and dispersed groups of users.	“Follow” relationship can build and strengthen social network ties by creating reciprocity. #hashtags generative capacity of forming groups/communities of people around common topics or ad-hoc issues. Generativity is produced thanks to the replicability of hashtags.	Zittrain (2006); Dwyer and Fraser (2006); Myers (2016); Sharma (2013).
Replicability		Hashtags and the ideas they express can be replicated several times by several users constructing meaning and cementing collective identities in the Twitter sphere. Replicability is achieved through Re-tweets and Reply.	Sharma (2013); Dwyer and Fraser (2016).

Table 2. A classification of digital objects attributes and their relationship to Twitter

Based on the review of a number of studies, the table illustrates the generic characteristics of a set of attributes and their relationship with Twitter digital objects. Since attributes characterize the functionalities of a digital object, they are important to understand affordances and, more precisely, what a user can do with a technology. For example, “editability” of tweets is limited. This means that users can delete but cannot modify a tweet. Therefore, by focusing on the attributes of digital objects it is possible to better understand the implications of Twitter functionalities in the realization of affordances in online patients communities.

Research Method

Data were collected by extracting tweets from the twitter chat of Great Britain Diabetes Online Community (GBDoc). As one can read from their website, <http://gbdoc.co.uk>, “#gbdoc was created by People With Diabetes (PWD) for People With Diabetes in Great Britain”. Every Wednesday between 9:00 and 10 pm members of this community can join the GBDoc chat through the hashtag #GBDoc.

The tweets from this chat were captured, visualized and analysed with the help of Chorus Analytics (<http://chorusanalytics.co.uk>), an analytics suite that captures data from Twitter’s application programming interface that is publicly available (Panagiotopoulos et al. 2014). Through the twitter hashtag #GBDoc, a sample of 4,402 tweets was collected between 18 November 2015 and 26 January 2016. Tweets were saved in a .txt file for the analysis. The text file was then imported into TweetVis the data analysis application of Chorus Analytics and divided into intervals (e.g. every 12 hours). It was then possible to visualize timelines of data and observe that the frequency of tweets was higher during the #GBDoc chat every Wednesday between 9:00 and 10:00 pm. Tweets falling within this time interval were sampled and exported into a separate text file. The new text file contained around 75 pages of tweets, which were analyzed through coding (Miles and Huberman 1994). Data were coded inductively by using the affordances and attributes categories in Tables 1 and 2 as a framework of reference, but also by being open to new codes. An example of codes and their interpretation is provided in the Appendix.

Coded data were interpreted by drawing on the literature of patients’ engagement and social media affordances. Data interpretation produced new insights into how affordances relationships influenced patients’ engagement together with the implications of digital objects attributes for the realization of

affordances. To protect the anonymity of the members of GBDoc, the tweets quoted in this paper have been paraphrased.

Results

The data analysis that follows illustrates the main affordances characterizing the activity of GBDoc on Twitter. The analysis draws a series of considerations on: the significance of these affordances for the members of GBDoc, how one affordance may lead to the realization of another affordance, the main digital objects attributes that support their realization.

Building a Support Network

In one of the chats, the facilitator asked GBDoc members who they considered to be their diabetes support network. Most answers highlighted the support that members could receive from GBDoc. For example, one member said:

“Except from one ex-girlfriend that still cares, I have been dealing with diabetes alone since 11. I am happy that I have found you [referred to GBDoc] a lot”.

In answering the question about the benefit from being part of #gbdoc as an “extended network”, another member mentioned that the online community had been extremely helpful given that he did not know anyone with diabetes in real life:

“[#gbdoc] has helped me a great deal since I don't know anyone with diabetes in real life!”

GBDoc's presence on social media is mainly on Twitter. Its members mostly interact with each other through the #gbdoc chat. For some users, GBDoc on Twitter was the only place where they could meet people with diabetes (PWD) and extend their network of support. Thus, “building a support network” of PWD was a fundamental affordance of the Twitter chat that enabled users' interactions and peer support. One user defined peer support within the GBDoc network in these terms:

“The GBDoc is a great resource. It really feels good and reassuring to return that support to others”.

Support was mainly associated with a full understanding of what it means to live with diabetes, which, compared to family and friends, only PWD have as expressed in this tweet:

“Family and friends can be really supportive, but only the #gbdoc can fully understand what suffering from diabetes means”.

It is also important to note that some community members can develop stronger ties with a selected number of users as manifested in this tweet:

“I consider part of my diabetes support network: me, my partner and a select number of people I've got to know through the #gbdoc”.

Thus, through Twitter, some GBDoc members have become more familiar and established closer relationships with other members (Bialski and Batorski 2010), which can ensure persistence of community exchanges.

“Building a support network” shares the characteristics of information exchange, social interaction and mutual support of the “connection” affordance found in Merolli et al. (Merolli et al. 2014). By bringing together patients that share the same experience with a disease, the affordance “building a support network” allows users to experience homophily and the sense of empathy that it generates in online communities on social networks (Nambisan 2011). In addition, by supporting the creation of cohesive networks of patients, this affordance could strengthen community identity, which, as found in other studies, can also develop empathy (Zhao et al. 2013) and sense of engagement (Ray et al. 2014).

In this regard, the following tweet hints to the role of the #GBDoc hashtag attributes “expansibility” and “generativity” in affirming the presence of GBDoc and the support network it represents as cohesive entities on Twitter:

“Our hashtag [#GBDoc] made almost 500,000 impressions in the last few hours. That is the strength of our community”.

Thanks to “expansibility”, hashtagging extends the reach of messages beyond the community’s network of followers. In addition, “generativity” relates to the number of impressions of a tweet, namely, the number of times people have seen a tweet on Twitter. Therefore, the greater the number of impressions generated by the hashtag #GBDoc the stronger the popularity and presence of a community in the Twitter sphere. Thus, the hashtag attributes “expansibility” and “generativity” are constitutive of GBDDoc presence.

The next tweet demonstrates how the GBDDoc community can provide immediate support compared to a care team. This reinforces the idea of GBDDoc as a support network:

“It’s strange to tweet before I call my care team, but you are here INSTANTLY. My care Team is there only when at their desk or within hours”.

This tweet also suggests that support is possible thanks to the functionality of Twitter affording instant communication. Community members can receive instant support thanks to the “instantaneity” of the message (or *tweet*) transmission (Papacharissi and de Fatima Oliveira 2012). “Instantaneity” is a new attribute, in this case, pertaining to the “tweet”, which can be added to those identified in the literature and summarized in Table 2.

Learning by Searching and Sharing Practical Information

Having analyzed the role of Twitter in “building a support network” for GBDDoc, “learning by searching and sharing practical information” appears to be one of the main affordances through which users were receiving support from their network. “Practical information” relates to specific needs and issues that patients may encounter in the daily management of diabetes. An example of how community members were experiencing support and learning by receiving such a type of information from their network is expressed in the following tweets:

“I could get instant practical support from #gbdoc when I did not know how to get rid of bubbles in my new pump”.

“I learned to use my pump by experimenting with it and by receiving advice and encouragement from #gbdoc rather than from carers/industry”.

The affordance “learning by searching and sharing practical information” is similar to the affordance “exploration” identified in Merolli et al. (2013, 2014). Related to exploration is another affordance, “adaptation”, which Merolli et al. (2013) define as the possibility to access information and support that best suit the changing needs of patients. In this regard, this research demonstrates how the information needs of online community members are satisfied, which is fundamental to “learning”.

The first tweet quoted above hints to “instantaneity”, an attribute of “tweets”, which, as discussed above, can afford instant communication. In this particular instance this attribute indicates the rapidity with which users can search for information and satisfy their information needs. In addition, the Twitter conversation in Exhibit 1 points to the long experience with diabetes by some community members as one of the strengths of GBDDoc. This conversation follows the tweets of two members who remembered the “old days” of mixing insulin in glass syringes:

P1: Remember mixing insulin in the old days, it was clear and cloudy. Very restricting #gbdoc

P2: #gbdoc I can’t believe some of us have so many years of experience with diabetes. Two people just said ‘glass syringes’ – that was a long time ago

P3 @P1: I used to mix cloudy insulin as well! #gbdoc

P4 @P2: That’s one of the reasons that makes the #gbdoc such an amazing place to be.

Exhibit 1. Extracts of a Twitter conversation about “cloudy” insulin

Community experience with diabetes is particularly helpful to the information needs of less experienced patients. For example, Exhibit 2 shows a university student with less than 7 years diabetes experience enquiring about the type of insulin she was using.

P1: A burning question: how do they establish the type of insulin you need? I was prescribed Humalog, but did not know about alternatives?
 P1: My team thought I was using Novorapid and I do not know the difference.
 P2: NovoRapid, Levimir, and Humalog... They are all the same.
 P3 @P1: I have used all three but some healthcare teams would not let you change easily.

Exhibit 2. Extracts of a Twitter conversation following one participant’s query about insulin

Notably, the conversation displayed in Exhibit 2 was not moderated, but it was started spontaneously by users while participating to #GBDoc chat. Prompted by a discussion question from the moderator, someone decided to have a conversation with other members of the community and ask for personal advice about treatment. The spontaneity with which community members asked for and shared information and advice between them is one of the key factors through which “learning” was afforded on Twitter. This is demonstrated in the Twitter conversation reported in Exhibit 3. After posting the picture of her blood glucose (BG) level, one user suggested that her BG meter was not working and received advise on how she could have it replaced. The conversation happened soon after the chat ended:

(picture shows BG level at 4.4)
 P1: I should be around 6.4 #gbdoc
 P2 @P1: your meter does not give you a correct reading?!?
 P1 @P2: its reading has consistently been 2mmol lower than it actually is!
 P2 @P1: I would have it replaced - consistently wrong equals to unnecessary finger stabs!
 P1 @P2: I thought you could replace it only if it fell off or gave no reading at all. I’ll ring them tomorrow :)
 P2 @P1: you should – I had the same problem and received a replacement. Keep the faulty one since they will want to have a look at it

Exhibit 3. Extracts of a Twitter conversation about the replacement of a BG meter

The spontaneity in exchanging information and advice indicates the “personal drive” and, therefore, the “sense of engagement” with which community members attend to the needs of their peers (Ray et al. 2014). “Sense of engagement” may be characterized by the cohesiveness among community members and the strong sense of identification with a community that comes with it (Ray et al. 2014; Zhao et al. 2013). Thus, by showing sense of engagement, community members demonstrate the strength of tie relationships within a community. Stronger ties through the realization of the affordance “building a support network” can intensify the exchange of practical information and, therefore, facilitate the realization of the affordance “learning by searching and sharing practical information”.

Self-presentation: Asserting Oneself

Users’ online identity was associated with their condition, the reason being that they wanted other people online to recognize them as Type 1 Diabetics. The online identity can be deduced by the diabetes-related terms included in user names such as: diabetic, carbon, insulin, endo, etc. and in the way users referred to themselves as T1D e.g. “type 1 diabetic” in their profile. The associations between users’ identity and diabetes are afforded by “associability”, which is not just an attribute of #hashtags, but also of such digital objects as @username and “user profiles”.

In this case, Twitter affords users the possibility to choose and control what they want to disclose about their identity and their medical condition. As found in other studies, this affordance takes the name of

“self-presentation” (Merolli et al. 2013; Merolli et al. 2014) and concerns users’ possibility of “asserting oneself” on Twitter. According to Merolli et al. (2014), by choosing the information they want to disclose about themselves, users control their interactions on social media. Hence, on Twitter, disclosing information about oneself and one’s own medical condition may increase patients’ online community interactions and presence on Twitter. As demonstrated in the tweet that follows, one user found out about #doc (diabetes online community) by meeting a community member on social media:

“#gbdoc I learned about #doc because I searched on Google ‘how to wear a pump with a dress’ and met @anonymous :)”.

Therefore, being identifiable as diabetic is the first step to attract new members in one’s community. As the community grows, the support network that it represents also grows. Hence, these findings suggest that the affordance of “self-presentation” can facilitate the realization of the affordance “building a support network”.

Yet, not all patients want to share information about their own disease. For example, some patients prefer to use such online platforms as blogs where anonymity is much easier to preserve. By hiding their own identities, some patients feel they can talk about their medical conditions more freely, particularly, if there is a social stigma attached to it (Merolli et al. 2013).

In comparison, the analysis of the user profiles and tweets of #GBDoc reveals a different scenario. In this case, users were actually keen to assert themselves as PWD and, in particular, “T1D”, i.e., as being diagnosed with Type 1 diabetes. Apparently, there is a stigma associated with T1D as being related to a wrong diet or body weight. Stigma is due to a widespread lack of understanding of T1D as an autoimmune disease where pancreas does no longer produce insulin (Butterly 2016). Some users resented the way some people confused T1D with T2D (Type 2 Diabetes) by claiming that diet can cure T1D as demonstrated in the tweet and profile description below:

“When I see a story about diabetes in the news, it upsets me since they don’t understand the difference between T1D and T2D, state that they found a cure, etc. #gbdoc”. (Tweet)

“Sorry I have stopped listening since you told me I could cure T1D with diet”. (User profile)

This last quote, in particular, reveals that disclosing information about one’s medical condition can also be a way to engage in “patient activism” to make people understand the real implications of T1D.

Narration

Another important affordance of GBDoc on Twitter is “narration” (Merolli et al. 2013; Merolli et al. 2014). This affordance emerged as users engaged with the online community to seek mutual understanding and comfort from their peers.

Being part of a support network like #GBDoc reflects the need to talk about life with diabetes as explained in this tweet:

“People think diabetes is a private issue, when I just want to talk about how difficult it is to live with it”.

Hence, Twitter, like other social media platforms, provide patients with the possibility of narrating their own experience (Merolli et al. 2013). This affordance encourages patients’ engagement with an online community as explained in this tweet by one user:

“#gbdoc has helped me to be open and talk about T1D [...] and to realize I am not alone while learning from others”.

Patients can tell stories about their life with T1D and they can also listen to similar stories from their community members. By sharing each other’s stories, users receive emotional support (Merolli et al. 2014) developing a stronger sense of empathy (Nambisan 2011) and closer relationships with their community members as explained in this tweet:

“By seeing people sharing the same questions, I know I am not alone and I feel much better”.

Thus, narration helps community members to support each other and strengthen their network ties. In this way, it facilitates the realization of the affordance “building a support network”.

Users experience greater empathy also thanks to the sense of closeness with other community members, which they perceive, particularly, when performing routine testing and treatments can be a source of anxiety for some diabetics as expressed in this tweet:

“Thanks to #gbdoc I am never alone, particularly, during the night when I have to test or treat”.

Such a sense of closeness can be achieved thanks to “generativity”, an attribute of digital objects, which enables spontaneous change by coordinated and dispersed groups of users (Zittrain 2006). This is an attribute of the “follow” relationship. Yet, it can be activated only if other community members follow back. It is only by creating reciprocity that the follow relationship can build and strengthen social network ties in an online community (Myers et al. 2014).

Feeling Empowered by Venting One’s Expertise About Diabetes

“Feeling empowered by venting one’s expertise about diabetes” is another important affordance elicited from the tweets analyzed. This affordance is linked to users’ strong desire to take full control of their diabetes as demonstrated in this tweet:

“I am the one who decides how to manage my diabetes. I can have full control on it. I choose what is best for me”.

The online community on Twitter gives users the possibility of showing their knowledge about diabetes while being recognized as the only “expert” in their diabetes as expressed in this tweet:

“#gbdoc my network lets me talk and manifest my knowledge while recognizing me as the only expert in MY diabetes”.

Another community member defines himself and other PWD as “the professionals” in managing diabetes:

“Healthcare professionals can monitor our condition and give advice only sporadically. We are the professionals #gbdoc”.

What emerges from these tweets is a new identity or “self-presentation” through which some community members present themselves as the “experts” and “professionals” in managing their own diabetes. The online community on Twitter allows them to perform this identity by letting them express their own knowledge and expertise about the disease. Hence, in this specific case, the affordance “feeling empowered by venting one’s expertise about diabetes” contributes to the realization of the affordance “self-presentation”. In other words, it allows users to act and be perceived by the other members of their community as diabetes experts. The understanding of how community members can share their knowledge and learn from others comes from their network as explained in this tweet:

“[People around me] have helped me understand how I should share my knowledge with others and, above all, what to learn from them #gbdoc”.

Thus, in addition to making people feel valued for the knowledge contribution that they give (Merolli et al. 2014), online patients’ communities on Twitter can provide users with a better understanding of what they can teach and what they can learn from others. This finding shows the implications of peer support through social media for patients’ self-management, particularly when peer support involves knowledge sharing. One challenge of self-management is to be able to recognize when knowledge from the community needs back up from a professional. In this regard, the conversation in Exhibit 4 shows how the online community can advise whether professional support should be sought. The conversation relates to an unexpected situation that emerged during one of the Twitter chat sessions. More specifically, one of the users participating to the chat felt unwell and used the chat hashtag #GBDoc to enquire about whether she should go to hospital or not.

<p>P1: Over what amount of ketones should one go to hospital?</p> <p>P2 @P1: do you also feel sick?</p> <p>GBDoc: How do you feel? More than 1.5 ketones is flagged as “severe illness”. Maybe call the out-of-hours services, stay safe!</p> <p>P1 @P2: I have not felt sick yet. I am trying to bring them down by drinking a lot of water.</p> <p>P2 @P1: are ketones 2.4?</p> <p>P1 @GBDoc: Thank you I feel odd but not been sick yet. Looking for an out-of-hour hospital number.</p> <p>P1 @P2: Yes!</p> <p>P2 @P1: go to hospital! Take a spare pump set with you!</p> <p>P1 @P2: just spoke to the hospital. They say to wait 30 min. If ketones do not drop, I will go in.</p>
<p>Exhibit 4. Extracts of a Twitter conversation started by a user asking advice on how to deal with an emergency situation</p>

Discussion

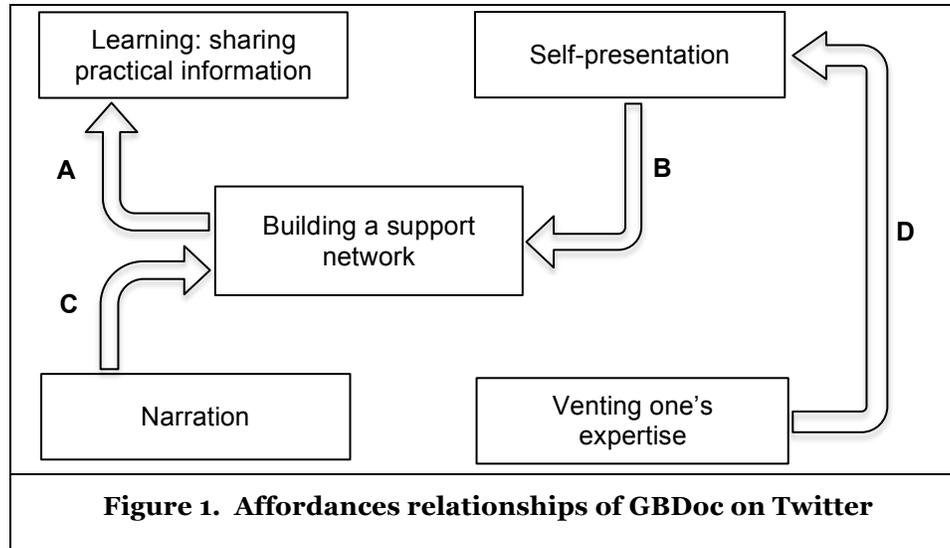
The Role of Composite Affordances

The first question that this paper seeks to answer is how affordances and their relationships influence patients’ engagement with online communities on Twitter. The data analysis presented in this paper has identified five main affordances, which are illustrated in Table 3.

Affordances	Description
Building a support network	The #GBDoc chat affords the creation of a support network for PWD, where users can find understanding, instant help, and be listened to.
Learning by searching and sharing practical information	Users can search and share practical information concerning specific needs and issues that they may encounter in the daily management of their diabetes.
Self-presentation: asserting oneself	Users associate their online identity with their medical condition to assert themselves as people with Type 1 diabetes.
Narration	By sharing each other’s stories, users establish closer relationships with their community members to seek mutual understanding and comfort.
Feeling empowered by venting one’s expertise about diabetes	Users can vent their expertise about diabetes and assert themselves as the only expert in their own diabetes.

Table 3. Affordances influencing patients’ engagement with GBDoc on Twitter

Based on the notion of composite affordances (Gaver 1991), the analysis has unveiled a set of relationships between affordances, which are represented in Figure 1.



The first affordance identified in this study is “building a support network”. The realization of this affordance lets users share similar concerns and needs about their medical condition enhancing their sense of empathy (Nambisan 2011). By supporting the creation of cohesive networks of patients, this affordance has the potential of strengthening community identity, thereby enhancing empathy (Zhao et al. 2013) and sense of engagement (Ray et al. 2014).

The next affordance, “learning by searching and sharing practical information”, relates to patients’ engagement with the online community to satisfy their information needs. Whereas previous studies on social media in healthcare have analyzed affordances as separate elements (Merolli et al. 2014), findings about this affordance demonstrate the importance of analyzing affordances as composite entities in order to fully apprehend their implications for patients’ engagement and outcomes. The analysis has demonstrated that outcomes from the realization of an affordance may be driven by other affordances and the social mechanisms that they entail. In particular, it was argued that the strengthening network ties through the realization of the affordance “building a support network” can generate a stronger drive and sense of engagement (Ray et al. 2014) in satisfying community members’ information needs, which, eventually, may enhance learning (arrow A). In addition, these findings complement previous research (Merolli et al. 2013; Nambisan 2011) by suggesting that community members may not perceive informational and emotional support distinctly. Sharing useful tips and information may actually be perceived as a way of giving and receiving emotional support.

The analysis also demonstrates how the realization of an affordance and its implications for patients’ engagement may be influenced by the structural characteristics of the online community. For example, it was shown how the personal drive and engagement in sharing information was related to the presence of more experienced patients willing to share their knowledge. This benefitted less experienced community members by enhancing their learning experience. These findings complement other research about the potential of online communities of improving healthcare outcomes by gathering together patients with different social and medical education backgrounds (Goh et al. 2016).

The next affordance is “self-presentation” through which community members could shape their identity on Twitter. By making themselves recognizable as T1D patients, they could easily get in touch with other patients and introduce them into the diabetes online community. The adherence of new members into the community can extend patients’ support network on Twitter showing the implications of self-presentation for the realization of the affordance “building a support network” (arrow B). “Self-presentation” is an example of how affordances can be involved in identity construction (Bernardi and Sarker 2013). Thus, like for the previous affordance, these findings show how the realization of an affordance may trigger social mechanisms, which can then have implications for patients’ engagement with an online community.

Disclosure of information about one's medical condition appeared to be related to an act of "patient activism" by some community members who wanted to change the stigma associated with T1D. Alongside previous research highlighting the desire for anonymity by some patients (Merolli et al. 2013; Josefsson 2005), these findings suggest that patients' enactment of "self-presentation" on social media constitutes their response to how others see their medical condition.

In the data analysis it was discussed how, "narration", another affordance, helped community members to support each other, thereby strengthening their network ties. Thus, the realization of "narration" plays an important role in "building a support network" (arrow C) within an online community.

The last affordance analyzed in this paper is "feeling empowered by venting one's knowledge about diabetes". Findings about this affordance reflect the way IT affordances may enable or constrain the performance of users' identities influencing their engagement with a technology and the outcomes that they produce by engaging with it (Bernardi and Sarker 2013). More specifically, the realization of this affordance allowed some users to present themselves and, therefore, perform their identity as "experts" of their own diabetes (arrow D). As a result, users felt motivated to engage with the community and share their expertise with other members. Findings also suggest that users' "self-efficacy" (Ray et al. 2014), i.e., their confidence about when and how they should use their knowledge to advise their peers, comes from the community itself. For example, one user implied how experiencing community relationships helped him realize the limits of his own knowledge and understand what he can teach and what he can learn from others. By recognizing such limits, the community may suggest members to seek medical advice as shown by the Twitter conversation with a user who was feeling unwell.

Some studies have raised concerns about the possible adverse effects of social media on health management. For example, Andersen et al. (2012) argue that there can be less quality of information if social media discussions are not moderated by a professional. In addition, increased access to medical information and knowledge on social media makes patients more aware and anxious about health problems augmenting demand on health services. The last findings in this study draw the attention to the implications that knowledge sharing in online patients communities has on balancing between self-management and professional support. More research in this area is needed.

The Role of Digital Objects

Social media like Twitter are different from specialized platforms hosting online communities of patients (e.g. Patients' Like me). Even though these platforms have been designed to afford the free input and flow of information from patients, designers have also created specific functionalities that direct patients' input into a determined direction leading to the emergence of intended data structures. Thus, patients' interconnections are mediated by system functionalities, such as the possibility of filtering user search based on similar symptoms or treatments (Kallinikos and Tempini 2014). Compared to specialized social networks such as Patients Like me, patients' online communities on Twitter do not have pre-defined data structures directing patients' input. Even though users' input may be guided through a series of questions from the moderator (Merolli et al. 2013), users' interactions are less controlled and more likely to lead to unexpected outcomes.

This section answers the second research question of this paper by discussing how Twitter digital objects supported the realization of affordances in GBDoc. As illustrated in Table 4, the realization of four out of five affordances identified could be linked to a set of digital objects attributes.

Digital objects	Attributes	Affordances
#GBdoc hashtag	Expansibility Generativity	Building a support network
Tweet	Instantaneity	Building a support network Learning by searching and sharing information
@username User profile	Associability	Self-presentation
“Follow” relationship	Generativity	Narration

Table 4. Digital objects attributes and their relationship with affordances

These findings deliver a greater understanding of how attributes of Twitter digital objects may afford possibilities of action influencing engagement with online communities of patients. For example, the “expansibility” and “generativity” of the hashtag #GBDoc were found to enhance the popularity and presence of GBDoc support network on Twitter, thereby supporting the realization of the affordance “building a support network”. Further research could explore whether these attributes may shape the collective identity of an online community of patients by strengthening its presence on Twitter (Sharma 2013).

The “instantaneity” with which a tweet is transmitted allows patients to receive immediate support from their community network. This includes retrieving the information they need as quickly as possible. As shown in the literature, the support received would then influence patients’ engagement with their online community (Nambisan 2011).

“Associability”, an attribute of the digital objects @username and “user profiles”, afforded associations between users’ online identity and diabetes. Such an attribute was linked to the affordance “self-presentation” and allowed patients to shape their patients’ online identity. As a result, they could easily establish connections with other diabetic users and introduce them into the online community.

Finally, “generativity” (Zittrain 2006) was also an attribute of the “follow” relationship. This attribute can build and strengthen network ties by generating a sense of closeness between dispersed community members who were narrating their stories about their diabetes. Yet, it is only by enacting reciprocity through a follow back that this attribute can work effectively. This is an example of how rules and norms governing online community relationships may play a role in activating the attributes of digital objects on social media.

Conclusions

This study has analyzed @GBDoc, an online diabetes community, in order to achieve a better understanding of the main affordances influencing patients’ engagement with online communities on Twitter. The analysis of affordances in this paper enriches the limited research in this area (Merolli et al. 2013; Merolli et al. 2014; Troncone et al. 2015). In particular, this paper makes two major contributions. First, it draws on the concept of composite affordances (Gaver 1991) to show the influence of affordance relationships on patients’ engagement with online communities on Twitter. In particular, it highlights the role of social mechanisms and community structures in influencing the realization of affordances and their implications for patients’ engagement.

Second, the paper extends our knowledge about the implications of the attributes of Twitter digital objects for the realization of affordances that influence engagement in patients’ online communities. It thus contributes to further our understanding about the materiality of social media and its implications for the realization of affordances in online patients’ communities (Spagnoletti et al. 2015).

The findings presented in this paper focus on the qualitative analysis of a sample of tweets extracted from the Twitter chat of one online community of patients. Therefore, there are limitations to the generalizability of these findings. Thus, further research about other similar communities of patients is

needed. The representation of the findings of this study in Figure 1 could constitute the basis for a more elaborated model to be tested with empirical research. Longitudinal studies could also unveil how complex relationships between affordances unravel across time furthering our understanding of patients' engagement with online communities.

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