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► **To cite this version:**

Raphaëlle Laubie, Christophe Elie-Dit-Cosaque. Exploring and Predicting Online Collective Action on Patients' Virtual Communities: A Multi-method Investigation in France. Thirty Third International Conference on Information Systems, ICIS 2012, Dec 2012, Orlando, United States. pp.12. hal-01630383

HAL Id: hal-01630383

<https://hal.science/hal-01630383>

Submitted on 7 Nov 2017

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Exploring and Predicting Online Collective Action on Patients' Virtual Communities: a Multi-method Investigation in France

Research-in-Progress

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Abstract

Virtual patients' communities are developing on the Internet. These communities allow frequent interactions among patients, who can share health-related information within an interactive environment. However, we know very little about what determines patients' online collective action on Web 2.0 social networks. Accordingly, this research-in-progress examines why patients interact with others and communicate on topics related with their disease through these virtual communities. Drawing on goal-directed behavior (MGB) and the expectancy-value (EVT) theories, we have developed a model for examining patients' interactions with virtual communities. This multi-method, qualitative and quantitative approach enables one to explore patients' interactions and measure the determinants of online collective action on virtual spaces. The results from the qualitative analysis of 54 interviews conducted with patients, patient's relatives, health 2.0 professionals, doctors and caregivers are discussed herein. This research is expected to increase our knowledge regarding the individual dynamics and interactions that surround online patients' communities.

Keywords: Health information systems, IT adoption, Social media

Introduction

In 2011, out of the total world population, 2.1 billion of people were Internet users, which points to an increase of 480% since 2000 (Nielsen Online, 2011). In this context, online interactions mediated by virtual communities are becoming significant endeavors for patients hoping to communicate about health-related issues (Pew Internet Research, 2011). For health reasons in particular, people are browsing through the Internet in order to find information (68%), to self-diagnose (46%) or to look for other patients' testimonials (39%) (Bupa Health Pulse, 2010). Patients are empowered by health-related, web 2.0 information technologies (IT) (Eysenbach 2008), and furthermore, these IT may also provide public health benefits. Indeed, they can reduce the number of necessary consultations with healthcare professionals, especially those regarding minor health nuisances, and help to redirect such resources to patients with more severe diseases (Bhatia and Sharma 2008). At times, these situations may contribute to substantial financial savings on the behalf of patients (Baker et al. 2005). For these reasons, health professionals wish to know in greater depth what determines individual interactions within health-related virtual communities. Accordingly, this research examines the determinants of patients' online collective action in the course of the adoption of patients' virtual communities.

The second generation of the Web, often known as *web 2.0* or *social web* (e.g., O'Reilly 2007), allows many individuals to interact with greater ease. It also provides collaboratively generated content that helps to enrich the information that is accessible to web users. Consequently, many researchers consider that it has completely changed the way that people seek, discover, and redistribute information (Ganley and Lampe 2009; Borland 2007). It has also profoundly changed the way that people build relationships and interact with one another (Boyd 2006). This is, for example, the case for patients' virtual communities, the use of which has grown tremendously in recent years (Eysenbach 2008; Smith and Christakis 2008; Orizio et al. 2010). However, due to the paucity of research in this domain, we still know very little about why patients engage in online collective action through these virtual communities. Further, given the context of usage of health virtual communities, the utilitarian perspectives of many of the extent adoption models (e.g., Davis 1989; Venkatesh et al. 2003) are probably not the most well-equipped for investigating online collective action in the context of health-related virtual communities. We may, for example, expect patients to differ somewhat from other users in more traditional settings of technological interaction. For example, patients may be significantly influenced by emotional factors due to conditions of mental fragility. Following this, and based on *expectancy-value* – EVT (Eccles et al. 1983) and *the model of goal directed behaviors* - MGB (Perugini and Bagozzi 2001) theorizing, we conceptualize a model that predicts intentional action and subsequent collective online action during users' interactions with patients' virtual communities. The research questions in this study are as follows:

- 1) What are the relevant expectancy values in the course of patients' interactions with virtual communities?
- 2) Do these expectancy values predict patients' desires and intentions regarding virtual communities' usage, and subsequently their engagement with online collective action?

In order to answer these research questions, we apply a rich, sequential, mixed-method approach (Creswell 2008). First, we have conducted a qualitative inquiry in order to investigate the facets of expectancy values, a process that has enabled us to ensure the validity of the content of these constructs. These values are conceptualized as determinants of patients' online collective action through virtual communities. The preliminary results of this qualitative phase are accordingly discussed in this research-in-progress. Second, by use of a questionnaire/survey, we aim to eventually measure the impacts of these expectancy values on desires, intentional action, and ultimately on online collective action.

This research is expected to contribute to both the literature and practice within the domain of Health Information Systems and IT adoption in two key aspects. Firstly, it uncovers the determinants of patients' engagement in interactions with and through virtual communities. Secondly, it conceptualizes and tests an enriched model of virtual communities' adoption. This model and our grounded, multi-method approach help us to go beyond some of the limitations imposed by traditional adoption models, and enable us to subsequently gain a more lucid understanding of patients' engagement with online collective action.

In the first section of this paper, we will discuss our chief theoretical anchor – the EVT and MGB – as applied to patients' online virtual communities. In order to answer our proposed research questions, we

then conceptualize a model and accordingly develop a number of hypotheses. Following this, we explain the design and methods for the research: 54 interviews have been conducted, and a questionnaire/survey is currently being developed that draws on the present qualitative inquiry. The different determinants of online collective action are then described and discussed. Following this, the expected contributions for research and practice are emphasized. We then conclude the paper by considering its implications for e-health and IT-adoption research.

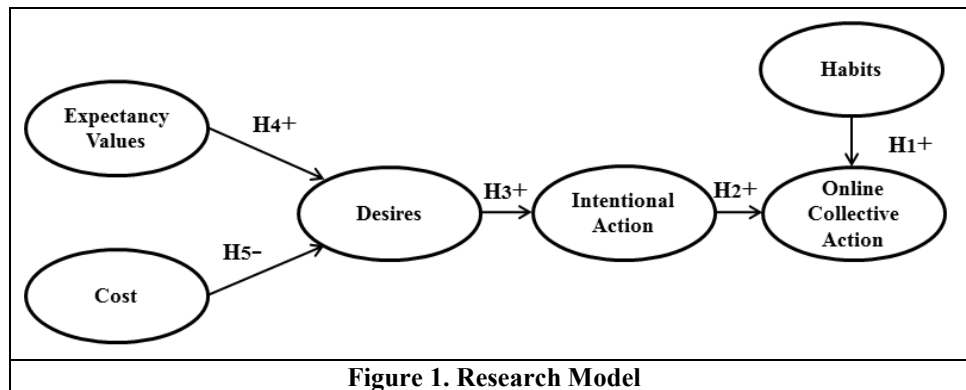
Theoretical Background

The *Model of Goal-directed Behavior* (MGB) (Perugini and Bagozzi 2001) and the *Expectancy-Value Theory* (EVT) (Eccles et al. 1983) both aim at explaining individual volitional behavior. The MGB draws on the Theory of Planned Behavior – TPB (Ajzen 1991), itself inspired by the Theory of Reasoned Action – TRA (Fishbein and Ajzen 1976). Essentially, the TRA explains a behavioral intention via the influence of subjective factors, such as one’s attitude towards an action to be performed (Behavioral Beliefs) or one’s beliefs about others’ attitudes regarding an action or subjective norms (Ajzen and Fishbein 1980). The TPB partially adopts the TRA’s conceptual framework. In fact, Ajzen (1991) introduced an additional predictor of intention and behavior, i.e. perceived behavioral control (PBC), or “the perceived ease or difficulty of performing the behavior, [which is] assumed to reflect past experience as well as anticipated impediments and obstacles” (Ajzen 1991, p.188). Following these insights, the MGB has facilitated the expansion of the TPB (Ajzen 1991) by introducing behavioral desire as a mediator of the influence of anticipated emotions on behavioral intentions (Perugini and Bagozzi 2001). In this, the MGB introduces emotions as a “new decision criteria with respect to a person’s goal” (p.80). Anticipated emotions are indeed posited to predict one’s behavioral desire to perform an action, which determines their behavioral intention and finally the behavior itself. However, the MGB must be adapted to contexts concerning the use and interactions brought about by the Internet and subsequent social media. Indeed, as explained by Hartwick and Barki (1994), the use of IT can be inferred only by considering the contextual background of the target users.

As it explicitly includes emotions, we believe that the MGB is more appropriate than the TPB in examining individual interactions with patients’ virtual communities than other adoption models such as the technology acceptance model (TAM) (Davis 1989) or the Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al. 2003). Further, Bagozzi and Dholakia have demonstrated the relevance of this model and its ability to “explicate the individual and social variables that shape the member’s we-intention to participate in virtual community interaction” (2002, p.4). However, Bagozzi and Dholakia (2002) identify only three antecedents of intentions to engage in virtual communities: *positive emotions*, *social identity* and *desires*. In the specific context of patients’ virtual web-based communities, we believe that their model should be enriched using a motivational and emotional perspective. From such a perspective, the *expectancy value model* helps one to distinguish between the different values that will predict intentions, while at the same time accounting for the influence of the factors identified by Bagozzi and Dholakia (2002). Drawing on Bandura’s (1977) theorizing about personal efficacy expectation (which focuses on outcome expectations), Eccles et al. (1983) have defined “beliefs about ability” as the “individuals’ evaluations of their competence in different areas” (Eccles and Wigfield 2002, p.119), and have subsequently identified four components related to these beliefs: *attainment value*, *intrinsic value*, *utility value*, and *cost*, which appear to be particularly insightful in the assessment of patients’ online collective action in virtual communities.

Model Formulation and Hypotheses

Following the two aforementioned theoretical anchors, this study examines users’ motives for joining online patients’ communities. In accordance with our theoretical background, the research model articulates virtual communities IT values and cost as determining online collective action through the mediation of patients’ intentional action and desires. Habits are posited to directly impact online collective action. We explain the rationale for these relationships below (Figure 1).



Online Collective Action

The concept of collective action (or *joint actions*) has been considered by Miller as the “most important species of interpersonal action,” and is defined as “the action that involves two or more agents performing individual action in the service of a shared end” (Miller 2001, p.5). In the context of patients’ virtual communities, members gather online in order to “communicate with each other around a specific health-related topic” (White and Dorman 2001, p.693).

Habits

Past behavior can be conceptualized in many different ways, such as frequency of behavior, recent behavior (Perugini and Bagozzi 2001), or habits. Habits have been defined as “the tendency to repeat past behavior in a stable context” (Ajzen 2002, p. 108; Ouellette and Wood 1998). Thus, even when dealing with IT use, habits refer to habitual behaviors rather than to behaviors guided by intentions (Limayem and Hirt 2003; Kim and Malhotra 2005). Some researchers found that habits have a significant effect on IT use that is “triggered by environmental cues” (Ortiz de Guinea and Markus 2009, p.440). Aarts and Dijksterhuis (2000) have further asserted that habits can be considered as links between goals and actions, activated by the environment; it contributes to the reaching of these goals through automatic behavior. Therefore, the more often the activation of a goal leads to the same behavior, the stronger the unconscious processes (Aaarts and Dijksterhuis 2000; Heckhausen and Beckmann 1990; Reason 1990). Concerning virtual communities, in addition to habits, we expect that the repeated connection of the patient will lead to Internet addiction, implying an extensive level of virtual communities interaction (Beard and Wolf 2001; Young 2004), and thereby of online collective action. Therefore:

Hypothesis 1: Habits are positively related to online action regarding virtual patients’ communities.

Intentional Action

According to Bagozzi and Dholakia (2001), individual participation in online community websites reflects *intentional (social) action*; these researchers assert, “the community member acts intentionally and that these actions have a collective basis in that both what is done and why it is done in the virtual community are determined by the community’s social characteristics” (p. 7). In the context of virtual communities, online collective action is explained by intentional actions (Dholakia et al. 2004). It implies a commitment and agreement from each protagonist to participate in joint-activity (Tuomela 1995; Tuomela 2005). As a result, intentional action will predict behavior or online collective action (Bagozzi and Dholakia 2002) in the context of patients’ communities. Therefore:

Hypothesis 2: Intentional action is positively related to online collective action regarding virtual patients’ communities.

Desires

While intentions control the action, desires are only conducive to the course towards it (Bratman 1987). Davidson has emphasized that acting intentionally is synonymous with having a reason in mind, namely a desire, which is accompanied by beliefs about how to achieve this desire. For example, a person’s primary reason for getting medical information will necessarily imply two elements, 1) the desire to get

medical information and 2) the belief that connecting to a medical information-related website is a means of obtaining medical information. Davidson (2001) further stresses that intentions can be influenced, depending on the conditioned evaluative judgments that may alter the appreciation of the situation. Including the concepts of desires and intentional action, the MGB postulates that past behaviors play a role in the action process, whether intentional or automatic (the latter referring to habits). Furthermore, it was observed that the MGB is a better predictor of intentional action than the TPB (Perugini and Bagozzi 2001). Arguably, desires act as mediating variables that transform motivational antecedents of online collective action into reasons for action (Dholakia et al. 2004). Therefore:

Hypothesis 3: Desires are positively related to intentional action.

Expectancy Values

Expectancy values are likely to determine the desires regarding the interactions with patients' virtual communities. A number of such values can be identified; for example, social values such as the attainment value are described by Eccles and Wigfield as "the personal importance of doing well on a task" (Eccles and Wigfield 2002, p.119; Eccles et al. 1983). This concept, linked by Markus and Wurf (1987) to one's self-schema, is defined by Dholakia et al. (2004) as a means to "understand and deepen salient aspects of one's through social interactions" (p.144). In the context of virtual communities, attainment values are likely to foster desires regarding online patients' communities use, as the individual sees such websites as a means through which he/she can reach his/her social goal. Relatedly, the utility value – or "how well a task relates to current and future goals" (Eccles and Wigfield 2002) – and intrinsic value – or "the enjoyment the individual gets from performing the activity or the subjective interest the individual has in the subject" (Eccles and Wigfield 2002) – has been shown to determine participation in virtual communities (Dholakia et al. 2004). Both these values have been referred to as "thinking or feeling" dimensions (Sweeney and Soutar 2001), or *utilitarian* and *hedonic* values (Grabner-Kräuter 2010). These utilitarian (purposive) and hedonic (entertainment) values were also studied by Dholakia et al. (2004), have been adapted from the MGB, and help to create the link between the MGB and EVT. Following this, both utilitarian and hedonic values are likely to foster desires. Indeed, patients will use websites because they view them as providing useful health-related information. The use in itself will contribute to the generation of positive emotions via entertaining features. Therefore:

Hypothesis 4: Expectancy values are related to desires regarding virtual patients' communities.

Cost

Cost relates to the "negative aspects of engaging in the task" (Eccles and Wigfield 2002). In social exchange theory, *trust* is a core component of a cost-benefit analysis with respect to social interaction (Roloff 1981). For interactions that take place in online communities, many researchers associate trust concerns with privacy concerns (e.g., Dong-Hee 2010; Fogel and Nehmad 2009). The press, for example, reported the unfortunate disclosure of several users' personal data (Read 2006). In the specific context of online patients' communities, trust is an essential dimension of *cost*. On the Internet, patients will be very concerned with the respect of privacy (Goldberg et al. 1997) and the accuracy of information (Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000), especially when they interact online with groups of people concerning very personal issues, such as health (Coulson 2005; White and Dorman 2001). Therefore:

Hypothesis 5: Cost will be negatively related with intentional action regarding virtual patients' communities.

Background Factors

In addition to these variables, we account for the role of a number of background factors in the model. Ajzen indeed has posited that "a multitude of variables may be related to or influence the beliefs people hold, such as: age, gender, ethnicity, socio-economic status, education, nationality, religious affiliation, personality, mood, emotion, general attitudes and values, intelligence, group membership, past experiences, exposure to information, social support, coping skills, and so forth" (Ajzen 2005, p.134), and has thus distinguished between the categories of personal, social and informational factors. Prior research has identified a number of virtual communities' (Lin 2008) and patients' (Rahmqvist 2001) characteristics that are relevant to the quantitative phase of the research. These factors are included as control variables in the model. *Demographics* comprise age, gender, education, socio-economic status, and marital status.

General individual factors comprise general attitudes about interacting with online communities, computer anxiety, perceived behavioral control about the online community, Internet experience, and media exposure. Health-related individual factors comprise disease handicap and disease stage. IT Factors comprise the perceived ease of use and the perceived usefulness of the online community.

Design and Methods

Research design

In order to answer to the research questions and to test the aforementioned hypotheses, we have applied a sequential, mixed-method design. This design includes a preliminary exploratory qualitative approach, followed by a quantitative approach that is used in order to test the research model (Creswell 2008).

Qualitative Approach

In the qualitative phase, we conducted semi-structured interviews (Roussel and Wacheux 2005) in France with doctors and caregivers, health 2.0 and web 2.0 experts, and patients and patients' relatives (Table 1). For each group, we stopped conducting interviews when semantic saturation was reached.

Interviewees	#	Focus
Doctors and caregivers	5	Feelings and concerns of the patients' population (from a medical standpoint)
Health 2.0 experts	13	Patients' motives for joining health 2.0 IT (from a medical and IT standpoint)
Web 2.0 experts	7	Individuals' motives to join online communities Contrasts between health communities and more traditional communities
Patients	21	Individual and social determinants for joining virtual communities (from a patient standpoint – community of breast cancer patients)
Patients' relatives	8	Individual and social determinants for joining virtual communities (from patients' relatives standpoint – community of parents of autistic children)
<i>Total</i>	<i>54</i>	

Our motivations for using this specific variety of interviews are multiple. Firstly, given the nascent stream of research, the theoretical framework we adopted had to be adapted to the selected field of inquiry. Secondly, we were expecting that certain constructs – in particular those regarding expectancy values –, would emerge from the patients' experiences and narratives. Hence, the partially inductive approach was expected to contribute to 1) the content validity for the constructs in the subsequent quantitative phase and to 2) the enrichment of the conceptual framework, which is grounded in both theory and actual human thoughts.

The patients who participated in the study were members of a breast cancer community and parents of autistic children. The breast cancer community's initial aim is to help patients to find information about their disease, to share their struggle in understanding it, and to put them in a position from which they can thoughtfully make decisions. It is comprised of approximately 10,000 French patients, located all over the world. Participation in the community is anonymous (if desired), free, and the platform is independent of any other renowned social networks. In contrast, the community of parents of autistic children is a small, closed Facebook group, which consists of just 97 persons. Its aims are similar to those of the breast cancer community, with an added focus on parents' confidence. Considering participants from these two different communities helped us to increase the variety of the user conditions that we were able to observe.

Most of the 54 interviewees were female, and all were adults. The anonymity of the respondent was guaranteed, and the interviews conducted were recorded and fully retranscribed. The responses provided us with primary information about individual motives for online collective action. It also helped us to identify the most relevant expectancy values to be included in the research model. To do so, the NVivo9 software was used to proceed to the thematic coding and data mapping (Bazeley 2007) of the interview material. The first author of the study coded the interviews after having set broad a priori categories, according to the research model and theoretical background. As we were also looking for potentially new concepts by examining how well data fit with the conceptual categories identified in the literature (Suddaby 2006), we also allowed for the possible emergence of other categories. In this ongoing coding process, which followed a grounded approach (Glaser and Strauss 1967), we hence created new categories from the interviews themselves. This process was repeated three times in order to ensure the nodes'

relevance. Recurrent interactions with the second author also ensured the accuracy of the coding process. Table 2 below details the different facets of the constructs that we have identified according to both this process and the literature.

Variable	Relevant Facet	Illustration*
Social Value	Group Norms (Tajfel 1982)	“Sharing a common vision is often verified at the very beginning. When we browse on a forum, we quickly realize that we share the same vision. You decide to leave because of conflicts about the purpose of the forum.”
	Belongingness needs (Baumeister and Leary 1995)	“Well, during my disease, although I was well surrounded by my family, I needed something else. I needed to talk to people, women sharing the same disease.”
	Exclusive Value – New dimension	“When it’s opened to everyone, as a result, it loses in terms of information. While in a site like <i>LesImpatientes</i> , we know that we will inevitably connect with sharp people sharing our concerns... and it is very reassuring.”
	Giving-Help – New dimension	“My role is different now, but obvious... I want to give back, and, if possible, to give answers. And often, the girls who subscribed ask us not to disappear, just to know that we’re still there, still in remission.”
Utilitarian Value	Information Needs (Flanagin and Metzger 2001)	“Yes. In fact, every time I had a question, every time I asked a question, I got an answer.”
	Instrumental Needs (Grabner-Kräuter 2010)	“Between doctor’s appointments, we have time to get anxious. On the network, we can speak freely whenever we need it. When girls explain what happened to them even in the reconstruction process, they really know what they’re talking about, almost as well as doctors and other medical professionals.”
	Isolation Rupture – New dimension	“Very few friends stay nearby when you are sick. And you do not want to bother them with your problems ... So, yes, it’s much easier to speak with someone who, himself, will understand and hear what you say because he experiences the same thing.”
Hedonic Value	Positive Emotions (Perugini and Bagozzi 2001)	“Emotions are present, regularly. In fact, when I’m in low spirits, I’m going on the network and it goes away.”
Cost	Inaccurate Medical Information – New dimension	“The big problem on the forum is that only patients participate with their own feelings, with their own knowledge... And they aren’t necessarily enlightened patients...”
	Privacy Protection – New dimension	“Control is important, as is the confidentiality of data. It was a prerequisite for me, if I was asked my name, I would be gone, because the Internet is risky”
	Negative Emotions (Perugini and Bagozzi 2001)	“When a person does his check-up and returns with a negative diagnosis, then you get a punch in your stomach because your fear is coming back and spreading...”
Online Collective Action (Dholakia et al. 2004)		“Well, I am determined to act by providing information and answers to people who ask questions, testifying that there is life after cancer. Yes, there is also the testimony that counts. Yes, there is the testimony that you can live well with illness...”

* Quotes from interviews with Breast Cancer Community’s patients.

The preliminary results of the exploratory, qualitative approach helped us to identify the main determinants of online collective action. The subsequent confirmatory, quantitative approach is expected to help determining whether the model accurately predicts online collective action. We discuss this next.

Quantitative approach

Based on the insights from the qualitative approach, the research model has been enriched and contextualized. Furthermore, the content validity of the model-variables has been improved, as we have identified multiple sub-facets of expectancy values with 3 dimensions for social value (group norms, belongingness needs, exclusive value, and giving-help), 3 dimensions for utilitarian value (information needs, instrumental needs, isolation rupture), and 1 dimension for hedonic value. We have also identified 3 dimensions for cost (accuracy of medical information, privacy protection, and negative emotions) and were able to contextualize online collective action and desires. In practice, and whenever possible, constructs’ measures will be adapted from prior research, and new measures will be developed when

necessary. Following this, a questionnaire will be developed, and a large cross-sectional survey (Creswell 2008) will be conducted over the Internet with the >10,000 users of the Breast Cancer Community's patients. Their anonymity will be guaranteed, which will also help in reducing any apprehension (Podsakoff et al. 2003).

Expected Contributions

This study examines the underlying determinants of online collective action on patients' communities. Upon completion, it will make three major contributions to research and practice. Firstly, it will help to create richer social media adoption models for health purposes. It combines two complementary theories (the MGB and EVT) in order to better examine the determinants of online collective action on patients' virtual communities. It also accounts for emotions, an important parameter for examining the patient's population. The multi-method approach contributes to the study's relevance (with a qualitative approach that enriches the research model with insights from patients' experiences) and rigor (with a subsequent quantitative study to measure the impacts of the determinants of online collective action).

Secondly, this study will respond to key challenges in IS adoption research, which has mainly examined *usage* without considering other kinds of interactions with and around the IT (Benbasat and Barki 2007), e.g. *online collective action*. Moreover, this research has mostly applied lean IT adoption measures (Burton-Jones and Straub 2006; Straub and Burton-Jones 2007), sometimes very far from what is experienced on the field (Straub et al. 1995). Specifically, the contextualized, multi-method approach will enable one to create and to test richer usage-related constructs based on patients' narratives and quantitative data.

From an e-health practice standpoint, a third contribution of this research concerns how virtual worlds can help to reduce perceived isolation and to improve patients' condition and day-to-day hardships. A major concern is that patients often feel alone, helpless, and demotivated when confronted with an illness. In this context, virtual communities can be viewed as a support for maintaining patients' social relationships. The results of this study are important because they will help Health 2.0 stakeholders to better acknowledge issues such as that of the kind of social community platforms that ought to be designed, the social media policy that may or should be applied, the messages that they may diffuse, or the factors they should modify so as to deliver a better user experience to patients in virtual communities. Eventually, the study's results will help us to more effectively take the disabled and ageing population's health challenges into consideration.

Expected Limitations and Future Research

This study will have three main limitations that will open avenues for future research. Firstly, the study is being conducted in France; therefore, we will not be able to generalize the findings to incorporate people from other countries. Future research may hence aim to extent the investigation to multicultural settings. Secondly, we have examined a breast cancer community, and a community of parents of autistic children. The research results may not apply to all other patients' online communities. For this, future research may be more inclusive in examining online collective action with patients from a broader range of communities. Thirdly, our patients' sample comprises a large majority of women, and it might not be possible to extrapolate the results to both genders. Future research may hence try to identify variations across genders regarding the determinants of online collective action on patient's online communities.

Conclusions

Following the MGB and EVT theories, this study conceptualizes a model to predict online collective action on patients' virtual communities. It proposes to apply a mixed, qualitative and quantitative approach. Health professionals and third parties have long been the ones that communicate (a limited amount of) information to patients in a top-down way. The Web 2.0 fosters online collective action, and subsequently the participation of patients in generating useful content in virtual communities. This may also bring about social benefits such as reduced isolation, which e-health professionals should leverage.

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