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Comprendre les Déterminants de l'Action Collective en Ligne

Le Cas des Patients 2.0

Understanding the Determinants of Online Collective Action

The Case of Patients 2.0

THESE

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INDEX

ACKNOWLEDGEMENTS.....	14
1 INTRODUCTION.....	21
2 MOTIVATIONS	35
2.1 SYSTEM USAGE AND SOCIAL BEHAVIORS IN WEB 2.0 ENVIRONMENTS	35
2.1.1 <i>The System Usage Issue in IS Research: Technology Adoption Models.....</i>	36
2.1.2 <i>Social Behaviors in the course of System Usage: the Need for Re- Conceptualizing Technology Usage.....</i>	38
2.1.3 <i>Users as Social Actors.....</i>	40
2.2 WEB 2.0 ATTRIBUTES	43
2.2.1 <i>Characteristics of Computer-Mediated-Communication</i>	44
2.2.1.1 <i>Attributes of Face-to-Face Communication.....</i>	44
2.2.1.2 <i>Attributes of CMC.....</i>	45
2.2.2 <i>Computer-Mediated-Communication in Health 2.0 Context</i>	46
2.3 HEALTH 2.0 AND THE ONLINE COLLECTIVE ACTION PHENOMENON	49
2.4 ONLINE COLLECTIVE ACTION IN HEALTH 2.0: ASSETS AND DRAWBACKS....	51
3 GROUP DYNAMICS AND COLLECTIVE ACTION IN ONLINE CONTEXTS	55
3.1 GROUP DEFINITION	56
3.2 GROUP DYNAMICS.....	57
3.3 FIELD FORCES AND HUMAN BEHAVIOR.....	58

3.4	INTEGRATING COMPUTER-MEDIATED-COMMUNICATION IN GROUP DYNAMICS: ONLINE GROUP DYNAMICS	59
3.4.1	<i>Online Group Definition</i>	59
3.4.2	<i>Field Forces in an Online Context</i>	61
3.5	COLLECTIVE ACTION	62
3.5.1	<i>Collective Action Concept</i>	62
3.5.2	<i>Collective Action in IT Contexts</i>	63
3.6	ONLINE COLLECTIVE ACTION	67
3.6.1	<i>Online Collective Action Concept</i>	67
3.6.2	<i>Driving and Restraining Forces of Online Collective Action: First Draft Model of Online Collective Action</i>	68
4	RESEARCH DESIGN AND METHODS	73
4.1	SEMI-STRUCTURED INTERVIEWS	75
4.2	RESEARCH FIELD	76
4.3	RESEARCH PARTICIPANTS	77
4.4	CODING AND ANALYSIS SEQUENCING PERSPECTIVE: CRITICAL REALISM PARADIGM	83
5	MODEL FORMULATION AND PROPOSITIONS	87
5.1	DRIVING FORCES OF ONLINE COLLECTIVE ACTION	88
5.1.1	<i>Gift Concepts: Social Value</i>	88
5.1.1.1	<i>Leveraging Gift Concepts</i>	88
5.1.1.2	<i>Online Gift-Giving Experiences</i>	93

5.1.1.3	Gift Concepts Transitive Knowledge from Patients' Perspective	96
5.1.2	<i>Social Values</i>	97
5.1.2.1	Functioning of Groups through Social Influence: Introducing Social Identity and Group Norms	97
5.1.2.2	Identification or Social Identity	98
5.1.2.3	Group Norms or Internalization	99
5.1.2.4	Exclusive Value Transitive Knowledge from Patients' Perspective	100
5.1.3	<i>Utilitarian Values</i>	101
5.1.3.1	Purposive Value: Information Needs and Instrumental Needs	101
5.1.3.2	Overcoming Isolation Transitive Knowledge from Patients' Perspective	102
5.1.4	<i>Hedonic Value</i>	102
5.1.4.1	The Role of Positive Emotions in Behavioral Action	102
5.1.4.2	The Role of Emotions in IS Research	105
5.1.5	<i>IT Artifacts: Utilitarian and Hedonic Values</i>	106
5.1.5.1	IT Artifacts	106
5.1.5.2	IT Artifacts Transitive Knowledge from Patients' Perspective	107
5.1.6	<i>Habits</i>	108
5.1.6.1	On Habits	108
5.1.6.2	Habits Transitive Knowledge from Patients' Perspective	110
5.2	RESTRAINING FORCES OF ONLINE COLLECTIVE ACTION	110
5.2.1	<i>Cost Value</i>	111
5.2.1.1	The Role of Trust in Behavioral Action	111

5.2.1.2	Trust Transitive Knowledge from Patients' Perspective.....	111
5.3	EMERGING MODEL OF ONLINE COLLECTIVE ACTION	113
6	MODEL ANALYSIS.....	119
6.1	CODING PROTOCOL.....	119
6.2	MODEL ILLUSTRATION: CATEGORIZATION RESULTS	122
6.3	DROPPED THEMES.....	123
6.3.1	<i>Dropped Variables for Driving Forces for Online Collective Action</i>	<i>124</i>
6.3.1.1	Role of IT Artifacts on Online Collective Action (Navigational Structure and Visual Appeal).....	124
6.3.1.2	Preference over Medical Process, Doctors Positive Perception and Boredom Avoidance	126
6.3.2	<i>Dropped Variables for Restraining Forces for Online Collective Action</i>	<i>127</i>
6.3.2.1	Complexity of Information	127
6.3.3	<i>Dropped Variables for Background Factors of Online Collective Action</i>	<i>128</i>
6.3.3.1	Open Virtual Space	128
6.4	RESULTING MODEL VARIABLES	129
7	MODEL RESULTS	135
7.1	RESEARCH QUESTION 1: CHARACTERISTICS OF ONLINE COLLECTIVE ACTION IN PATIENTS' VIRTUAL COMMUNITIES.....	136
7.2	RESEARCH QUESTION 2: DETERMINANTS OF ONLINE COLLECTIVE ACTION	138
7.2.1	<i>Driving forces for Online Collective Action</i>	<i>138</i>

7.2.1.1	Utilitarian Value: Information Needs, Overcoming Isolation, Instrumental Needs.....	138
7.2.1.2	Social Value: Belongingness Needs, Group Norms, Giving-Help and Exclusive Value.....	140
7.2.1.3	Hedonic Value: Positive Emotions.....	145
7.2.2	<i>Restraining forces for Online Collective Action.....</i>	<i>146</i>
7.2.2.1	Cost Value: Negative Emotions, Inaccurate Medical Information, Privacy Protection	146
7.3	SURROUNDING CONSTRUCTS OF ONLINE COLLECTIVE ACTION.....	149
7.3.1	<i>Benefits of Online Collective Action</i>	<i>149</i>
7.3.1.1	Belongingness Speed and Strength	149
7.3.1.2	Enlightened Patients.....	150
7.3.1.3	Role in Healing	150
7.3.2	<i>Background Factors</i>	<i>152</i>
7.3.2.1	Habits.....	152
7.3.2.2	Females Disinhibition.....	152
7.3.2.3	Information Control	153
7.3.2.4	Online Clinical Advices Requirement	153
7.4	SUMMARY OF RESULTS.....	155
8	DISCUSSION AND CONCLUSION	159
8.1	COMING BACK TO THE RESEARCH QUESTIONS	160
8.1.1	<i>Discussion on Research Question 1.....</i>	<i>160</i>
8.1.2	<i>Discussion on Research Question 2.....</i>	<i>161</i>

8.1.2.1	Driving Forces of Patients' Online Activity and Emergent Categories..	161
8.1.2.2	Driving Forces of Patients' Online Activity and Gift Concepts.....	162
8.1.2.3	Restraining Forces of Patients' Online Activity and Emergent Categories	
	164	
8.2	CONTRIBUTION	165
8.3	LIMITATIONS AND FUTURE RESEARCH	169
8.4	CONCLUSION	171
9	ANNEXES	175
9.1	ANNEX 1: PROPOSITIONS	175
9.2	ANNEX 2: DICTIONARIES OF A PRIORI THEMES#1	177
9.3	ANNEX 3: DICTIONARIES OF THEMES#2.....	178
9.4	ANNEX 4: DICTIONARIES OF THEMES#3.....	181
9.5	ANNEXE 5: RESEARCHER PROFILE	184
9.5.1	<i>Teaching Experience, Corporate Experience and Education.....</i>	<i>184</i>
9.5.2	<i>Presentations and Publications in Conferences with Peers Reviews</i>	<i>186</i>
	BIBLIOGRAPHY	189

TABLES

Table 1. Collective Action..... 66

Table 2. The Research Approach..... 74

Table 3. Interviews 79

Table 4. Interview Guide in Preliminary SDCI 80

Table 5. Interview Guide in Patients and Patients’ Relatives SDCI 82

Table 6.1 Gift Concepts as an Utilitarian Value 91

Table 6.2 Gift Concepts as a Social Value 92

Table 7 Online Gift Concepts as Utilitarian, Social and Hedonic Values 95

Table 8. IT Artifacts as Utilitarian and Hedonic Values 107

Table 9. Categorization of IT Artifacts and Role on Online Collective Action 125

Table 10.1 Categorization and Leading Concepts - Driving Forces 130

Table 10.2 Categorization and Leading Concepts - Restraining Forces 131

Table 11. Categorization and Secondary Concepts..... 131

Table 12. Categorization of Online Collective Action..... 137

Table 13.1 Categorization and Leading Concepts – Utilitarian Value 140

Table 13.2 Categorization and Leading Concepts – Social Value 144

Table 13.3 Categorization and Leading Concepts – Hedonic Value 145

Table 14 Categorization and Leading Concepts – Cost Value..... 148

Table 15.1 Categorization and Secondary Concepts - Benefits of Online Collective Action
..... 151

Table 15.2 Categorization and Secondary Concepts – Background Factors 154

Table 16.1 Open Codes for Driving Forces of Online Collective Action..... 177

Table 16.2 Open Codes for Restraining Forces of Online Collective Action.....	177
Table 17 Open Codes for Online Collective Action.....	177
Table 18 Open Codes for Background Factors of Online Collective Action	177
Table 19 Open Codes for Benefits of Online Collective Action	177
Table 20.1 Open Codes for Driving Forces of Online Collective Action	178
Table 20.2 Open Codes for Restraining Forces of Online Collective Action.....	179
Table 21. Open Codes for Online Collective Action	179
Table 22. Open Codes for Background Factors of Online Collective Action	180
Table 23. Open Codes for Benefits of Online Collective Action.....	180
Table 24.1 Open Codes for Driving Forces of Online Collective Action	181
Table 24.2 Open Codes for Restraining Forces of Online Collective Action	182
Table 25. Open Codes for Online Collective Action.....	182
Table 26. Open Codes for Background Factors of Online Collective Action	183
Table 27. Open Codes for Benefits of Online Collective Action.....	183
Table 28. Researcher Profile – Teaching Experience	184
Table 29. Researcher Profile - Corporate Experience.....	185
Table 30. Researcher Profile - Education	185
Table 31. Researcher Profile – Presentations and Publications in	186
Conferences with Peers Reviews	186

FIGURES

Figure 1 First Draft Design of Model of Driving and Restraining Forces of Online Collective Action 69

Figure 2 Critical Realism Research Design75

Figure 3 Emerging Model of Driving and Restraining Forces of Online Collective Action (before coding) 115

Figure 4 Model of Driving and Restraining Forces of Online Collective Action (after coding)132

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“The meeting of two personalities is like the contact of two chemical substances: if there is any reaction, both are transformed.”

Carl Jung (1875 - 1961)

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Thesis Abstract

Virtual spaces are blossoming on the Internet. More and more, those spaces deal specifically with health-related issues featuring a dynamic online activity, with community sites having 24 times more social media activity on average than any of the health industry companies (PwC 2012). However, research still lacks knowledge about patients' motives for joining virtual patients' communities. In order to respond to the research gap, this study addresses the following questions:

- i)* What are the characteristics of online collective action among patients in dedicated virtual communities?
- ii)* What are the determinants of patients' online collective action?

Some researchers have already explored related issues. For example, following Perugini and Bagozzi's model of purposive behavior (2001), Dholakia et al. (2004), explored the determinants of virtual community participation. Adopting a different approach, Grabner-Kräuter (2010) has shown the relevance of the role of trust in the understanding of online social networks. Those contributions notwithstanding, we still have very little knowledge about individual and social determinants of patients' adoption of virtual communities. In fact, while a growing number of people gather online through Web 2.0 technologies, information systems research (IS) has hardly conceptualized and examined online collective action. Drawing on the characteristics of collective action, the Lewin (1947) Field Theory, the Expectancy-Value Theory (EVT) (Eccles et al. 1983), gift concepts and positive emotions in behavioral action, this research further explores online action dynamics among patients, actors in health-related online communities.

A qualitative approach was adopted. Semi-structured interviews have been conducted with 25 doctors, caregivers, Health 2.0 professionals and Web 2.0 experts. Following this, 29 patients and patients' relatives have been interviewed. The interviews have been retranscribed and analyzed. The results of this study emphasize the patients' standpoints about their online collective action, together with their fears or appeals for engagement.

Hereby follows the discussion and contributions of the research, and its implications for future work in the Web 2.0 domain.

Keywords: *Patients 2.0, Health 2.0, Virtual Communities, Online Collective Action, Gift Concepts, Field Theory, Expectancy Value Theory, Model of Goal-Directed Behavior, Emotion, Trust*

1 - INTRODUCTION

1 INTRODUCTION

Health 2.0 has changed the link between individuals and health related information (Eysenbach 2008; Frost and Massagli 2008). Although the traditional health system is the first player in case of health issues (Dedding et al. 2010), many patients consider that specialized websites offer valuable connections and support to themselves and their families (White and Dorman 2001; Smith and Christakis 2008). However, such patients' empowerment still suffers from the medicine paradox, assuming that 'doctor knows best' and thus neglecting to illuminate patients' needs (Bos et al. 2008). This is probably why some electronic platforms are often being developed without precise indications concerning patients' requirements, characteristics, and motives for joining and interacting on a specific online community.

This is also probably because research has developed very little knowledge about the concept of online collective action, and its determinants for patients in Web 2.0 contexts. In order to address those research and practical gaps, this study investigates the individual and social parameters that drive patients to join such online communities. The research addresses two research and practical questions.

1. What are the characteristics of online collective action in the context of patients' virtual communities?
2. What are the individual and social driving and restraining forces of patients' online collective action?

Before seeking to address the research questions, we conducted preliminary interviews with Doctors, caregivers, Health 2.0 and Web 2.0 experts. We then conducted interviews with patients and patients' relatives.

Researchers have already explored some aspects related to users' motives for joining virtual communities. For example, in their study, Dholakia et al. (2004) adapted the Perugini and Bagozzi (2001) goal-directed behavior model to examine the use of social networking websites.

Yet first, Perugini and Bagozzi expanded the theory of planned behavior (TPB) (Ajzen 1991) in order to recast and explain decision making behavior. By introducing desire as a mediating variable for intention formation they operated a severe conceptual shift resulting in the Model of Goal-Directed Behavior (MGB).

The ensuing model, MGB (Perugini and Bagozzi 2001), is an attitude-based model explaining purposive behavior positing that desire and intention are distinct concepts. Desire captures the motivational drive towards intention, and therefore future orientation, in pursuit of a goal, taking into account outcomes that would be considered beneficial or detrimental. In this regard, anticipated emotions – positive or negative - are a predictor for desire. It also postulates that past behavior has a role to play in the action process, whether it is intentional or automatic, the latter referring to the notion of habits (Ajzen 2002). Therefore, MGB differs from the TPB as it includes additional dimensions such as emotions, motivation and habits (Shiu et al. 2008). So, we suggest that these drivers of purposive behavior should be taken into account in the context of

patients' virtual communities. All the more so since it has been observed that MGB gives better results than TPB in predicting intentional action (Perugini and Bagozzi 2001).

In the IS domain specifically, prior models have been used to examine technology adoption in different contexts with Web 1.0 and Web 2.0 technologies around the concept of system usage (Hofmann 2002; Bokhari 2005; Straub and Burton-Jones 2007; Burton-Jones and Gallivan 2007; Usluel and Mazman 2009).

For example, the Technology Acceptance Model (TAM) (Davis 1989) has been validated as an effective framework describing users' adoption of IT linking behaviors to attitudes and beliefs, namely ease of use and usefulness "that are consistent in time, target, and context with the behavior of interest" (Wixom and Todd 2005, p.85).

The unified theory of acceptance and use of technology (UTAUT) (Venkatesh et al. 2003) modifies TAM, identifying four determinants (performance expectancy, effort expectancy, social influence, and facilitating conditions) for behavioral intention, itself determinant of usage. Gender, age, experience, and voluntariness of use mediate these aforementioned determinants with regard to behavioral intention.

Then, based on the work of Shannon and Weaver (1963) and Mason (1978) as well as empirical management information systems (MIS) research studies from 1981 to 1987, the ten year update IS Success (Delone and McLean, 2003), acknowledging that the role of IS has changed and progressed during a ten year span, draws a multidimensional model of IS success.

Nevertheless, based on TAM (Davis 1989), Burton-Jones and Straub (2006) explain that they doubt that usage intentions and usage behavior dependent variables of TAM

capture the very notion of acceptance, urging “researchers to provide systematic evidence for which usage measures, if any, are valid proxies for related constructs and to determine which other constructs, if any, are good proxies for system usage” (Burton-Jones and Straub 2006, p.241). Bokhari (2005) further highlights that research does not offer congruent conclusions linking system usage and user satisfaction. Similarly, regarding on the IS Success Model (DeLone and McLean, 2003), Hofmann (2002) warns about the implications of collective phenomena appending a multilevel nature for system usage.

However, some researches drew on several of the aforementioned IS adoption models such as TAM or ISM to explain users adoption in terms of ease of use and usefulness in the Web 2.0 context. They demonstrated that some variables may contribute to the gathering of a critical mass of users (Shin and Kim 2008; Shin 2008; Wu et al. 2008). However, when those gathering phenomena are taken into account in online contexts, IS success, as per DeLone and McLean (2003) updated IS success model, would require other dimensions to be taken into account to capture users’ adoption determinants. For example, in the case of corporations: taking into account corporate culture, the support of top management, proper leadership, communication and motivation and training of end-users should be further studied, as explained in the case of web-based collective action (Trkman and Trkman 2009).

In addition, with respect to the Unified Theory of Acceptance and Use of Technology (UTAUT) Model (Venkatesh et al. 2003), Burton-Jones and Gallivan (2007) also emphasize concerns about the lack of multilevel in this theory as constructs are

conceptualized at the individual level. As a result and in spite of the conceptual strength of all those models for understanding system usage, we believe that, alone, they do not provide sufficient basis for examining online collective action, which is embedded in system usage in the Web 2.0 context.

In sum, those models fail to address four main gaps.

First, those models all focus on system usage and remain silent on the fundamentally *collective* nature of the usage and of the benefits of Web 2.0 technologies. In contrast to Web 1.0 IT, Web 2.0 IT usage underlies *collective action*. For this, conceptualizing Web 2.0 system success through the concept of system usage would not be sufficient as its fundamental principles and benefits lie in the collective use of the technology (Burton-Jones and Gallivan 2007; Rheingold 2003). In this, as argued by Lamb and Kling (2003), users are fundamentally social actors who interact through technologies and should be treated as such.

Second, those models do not or hardly account for the role of emotions in the course of individual interactions with technology and whether those positive or negative emotions play a role in the results of IT introductions to people (Beaudry and Pinsonneault 2010). Arguably, as they imply frequent interactions among people, Web 2.0 technologies are frequent occasions for emotional processes to occur. This is especially the case of patients 2.0 contexts, where people are looking for information about their – sometimes severe - health issues (Arnst 2008). By neglecting emotions, “traditional” adoption models such as TAM, UTAUT, or ISM, are insufficient to provide in-depth insights about patients’ interactions with IT. By way of contrast, as it includes emotions adding to TPB

the affective components of desire for further goal setting, we believe MGB provides additional insights as compared with models such as TAM for predicting users' online behavior (Dholakia et al. 2004).

Third, interestingly, all those models are very silent on the nature of the links among actors of social websites. Social actors interacting on Web 2.0 websites have both instrumental and non-instrumental behaviors led by their desire to share their experience with others. Online collaboration requires strong social ties between the giver and the receiver and a high level of trust between social actors (Bergquist and Ljungberg 2001). While information is shared for free, intense collective action results in a rich and valuable website for e-patients. Arguably, the concept of gift may help to further our understanding of those links. However, to our knowledge, IS research has not examined in sufficient depth that concept in the online environment (Bergquist and Ljungberg 2001) due to the influence of primitive cultures' concepts that belong to *real* worlds as opposed to virtual spaces (Mauss 2002). Nevertheless, the gift concept is a critical one when examining social actors' interactions in virtual environments, especially in the medical sphere.

Fourth, prior research has already pointed out the limitations of traditional adoption models. Benbasat and Barki (2007) or Straub and Burton-Jones (2007) for example explain that existing research on technology adoption and usage has studied a too narrow set of variables around the concept of system usage, which has been conceptualized in a too lean manner. Benbasat and Barki further argue that adoption research has hardly sought to examine important mediators or moderators of system usage such as those in the realm of emotions. In order to answer some of those gaps, as

mentioned before, Burton-Jones and Straub (2006) argue that it is necessary to reconceptualize system usage and call for the development of more contextualized usage variables. Unfortunately, little-to-no indications have been given to better understand how to account for Web 2.0 contexts, and what system usage *is* in those contexts.

For all those reasons, we argue that the existing theoretical frameworks have to be adapted to our field of inquiry. Therefore an exploratory approach has been applied in the current research.

Following the emerging insights from the field and theories such as MGB, we develop a model for understanding patients' online collective action that specifically includes the concepts of emotions and gift. Furthermore, we are not convinced that the way concepts and categories are coupled for standard users (Dholakia et al. 2004) is relevant for patients, considering the hardship they may be enduring and a mental state that may be weakened. We investigated the role of gifts, from Mauss' (2002) initial work – also highlighted in open source communities, in order to explain the successes of such collaborative entities, work and outputs (Bergquist and Ljungberg 2001). This exploration is expected to provide additional knowledge about the determinants of patients' online collective action. Positives emotions, a core concept that triggers the desire to act in MGB (Perugini and Bagozzi 2001), is also studied in this context of participation and help-giving between patients suffering from the same disorders. However, all these concepts have been adapted to the particular aspects of patients' usages and needs.

A *partially* grounded approach has been applied in order to further investigate online collective action in Web 2.0 contexts. While we believe existing theories provide relevant insights to examine this issue, we believe they are insufficient to provide a complete account of online collective action in health contexts. That is why we have decided to ground our research on both the field and theory. So doing allows us to benefit from emerging insights from the field, while contributing to knowledge in a cumulative way. Patients' needs and interactions on Web 2.0 platforms have been examined carefully from the very outset of the research. In this, interviews have been conducted, in an attempt to tightly connect the research to the virtual communities under study, incorporating their situational and social backgrounds for a better understanding. Our approach aimed at going beyond a 'pure' positivist approach, sometimes depicted as naïve realism "in which reality is comprehensible and knowledge can easily be captured and generalized in a context-free form" (Zachariadis et al. 2010, p.5), or a 'pure' interpretivist approach that excludes causal explanation "in early debates in the philosophy of social science concerning understanding versus explanation and on whether reasons could be causes" (Sayer 2000, p.96). Indeed, specifically defining critical realism's scope Zachariadis et al. state:

"instead of looking for social laws we should be looking for causal mechanisms and how they work. According to critical realists, consistent regularities are only likely to arise under special circumstances in closed systems" (2010, p.5).

Following this, our posture draws from critical realism, which we believe helps provide the appropriate research design addressing the ontological and epistemological flaws of positivism Zachariadis et al. (2010), consistent with the way we consider how knowledge

is constructed. In practice, the constant back and forth between the patients' inputs gleaned during the interviews, to the insights brought by the literature, have shaped our research design consistent with our critical realist approach. This approach allowed us to bring additional relevance to this work, where concepts coming from the field were compared with the literature in an exploratory quest for answers (Mingers 2000; Mingers 2004).

Firstly, preliminary interviews helped us identify which environment would be relevant for our research.

Secondly, the first exchanges with patients guided us through an in-depth literature review, however constantly directed by patients' interviews. These first contacts with the field allowed us to determine which theories would fit with the reality of the environment and to develop a first draft model accordingly. Both the existing literature study and our perception and understanding of the environment in compliance with existing theories contributed to the model drawing. The initial factors for the model basis were therefore streamlined, resulting in the model's propositions. While revisiting the literature, we proceeded to an inductive approach that helped to harness a better construction of the whole conceptual framework. Taking into account the implications of computer-mediated communication (Sproull and Kiesler 1986), considered as the means for isolated persons (Hugon 2010) and a fortiori for patients' interaction, we have explored the functioning of groups, influenced by social norms and self-identity (Kelman 1958). Further considering some of the specificities of patients' community members that intend to participate online, we further examined the gift-giving literature and its relevance for answering our research questions (Larsen and Watson 2001).

Finally, helped by our theoretical framework, an in greater depth field exploration allowed us to unearth literature knowledge as well as transitive knowledge. All these concepts and dimensions were associated with the model structure. As a result, transitive knowledge is a critical component that outlines the environment chosen, filling in the research gaps. Concepts were constantly compared with knowledge from literature that they would refer to, and converge towards. It contributes to the rise of constructs that result in the creation of an original model, instigated by literature's enlightenment and the field's rationalization throughout the whole research process. Based on those theoretical anchors, and in order to answer our research questions, we applied a qualitative methodology. We conducted 54 semi-structured interviews (Roussel and Wacheux 2005) with patients, Web 2.0 experts, physicians, and other relevant informants, according to the research topic.

This research makes several contributions to research and practice. Firstly, in answering those research questions, this study conceptualizes and illustrates online collective action in a Web 2.0 context. Secondly, it gives primary insight for an online collective action model in order to better acknowledge the commitment process for a definite type of patient. This model emphasizes the importance of information and emotional needs in the engagement process, leveraging the largely unexplored concept of gift-giving and emphasizes the drivers and impediments of online collective action in Health 2.0 environments. Finally, it highlights the tangible benefits of continuing involvement as well as the pitfalls of these virtual spaces. In so doing, it helps the designers of web communities to understand what values' features and type of interactions matter in

patients' community contexts and can give further insight into what would be desirable with regard to the formulation of patients' needs.

Our work is structured as follows. Firstly, we depict our motivations to gain further knowledge about individual and social determinants of participation in Health 2.0 online communities. Following this, we present the material, methods and designs for this research and its related procedures. Following both preliminary insights from the field and the literature, a model has been developed. This model is then compared to further field insights. Then, those results are discussed and the contributions are described. We conclude the dissertation with the research limitations and the avenues for further research, together with the perspectives for the patients and Health 2.0 environments.

2 – MOTIVATIONS

2 MOTIVATIONS

In order for individuals to interact online, system usage has to be taken into account and fully understood as it will lead to users' satisfaction that will drive action. However, in the Web 2.0 environment the satisfaction alone provided by system usage may not suffice to lead to online collective action. In this respect, this section highlights what possible gaps remain in system usage theories that fail to address Web 2.0 social behaviors and their linkage with online interaction.

2.1 System Usage and Social Behaviors in Web 2.0 Environments

System usage has been widely discussed in IS research (Barkin and Dickson 1977; Straub et al. 1995; Straub and Burton-Jones 2007) and often used as a surrogate measure of IS success or user satisfaction.

Besides, system usage construct suffers from a too simplistic approach (Lee 2000; Schwarz and Chin 2007), a vague definition (Burton-Jones and Straub 2006) despite widely recognized milestones achieved through the establishment of founding models, namely TAM (Davis 1989) or UTAUT (Venkatesh et al. 2003; Venkatesh and Bala 2008). Furthermore, in the social environment these theories fail to capture the multilevel nature of system usage (Burton-Jones and Gallivan 2007) which is specific to the operation scheme of virtual communities, triggering online collective action.

Before elaborating on the Health 2.0 online collective action phenomenon, we wish to identify these breaches in IS research when it comes to system usage in the social

environment. These gaps in the comprehension of virtual spaces ought to be considered as a primary aspect of our research motivation.

2.1.1 The System Usage Issue in IS Research: Technology Adoption Models

Coming back to fundamentals of Information Systems' theories, Davis explained the use of technology by the Technology Acceptance Model (TAM) (Davis 1989), extensively inspired by the Theory of Reasoned Action (Fishbein and Ajzen 1975).

In his model, Davis (1989) removed attitudes as a mediating variable between behavioral beliefs and intention. Therefore, perceived usefulness and perceived ease of use lead to the behavior of technology use, excluding attitudes as a predictive value of intention. Davis defined perceived usefulness as the degree to which a person believes that using the system will enhance his job performance; perceived ease of use, as the extent to which a person believes that using the system will be effortless. Although it has been subjected to multiple revisions (Venkatesh and Davis 2000; Venkatesh 2000), leading to UTAUT (Unified Theory of Acceptance and Usage Theory) (Venkatesh et al. 2003; Venkatesh and Bala 2008), TAM was a significant achievement for IS research and the most widely cited model in the IS field.

With UTAUT, Venkatesh et al. (2003) defined a unified theoretical model that combines eight previously established models, namely Diffusion of Innovation, Theory of Reasoned Action, Theory of Planned Action, Technology Acceptance Model, Combined TAM and TPB, Motivational Model, Social Cognitive Theory, Model of PC Utilization. UTAUT was proven to offer better results than the eight theories that inspired the model.

The IS Success Model (Delone and McLean 1992; Delone 2003) is a widely acknowledged model in IS research explaining IS success. Its first release (Delone and McLean 1992) is a multidimensional measurement model “providing a scheme for classifying the multitude of IS success measures that have been used in the literature, into six categories” (Seddon 1997, p.240); namely system quality, information quality, organizational impacts, individual impacts, satisfaction and use. The model adds on temporal and causal interdependencies of these categories.

In its second release, the model has been amended due to criticism of “confusing meanings” of use (Seddon 1997, p.240). However, the warning of use meaning remains challenging and still requires nature, extent, and appropriateness of measurement of use to be mitigated (Delone 2003; Petter et al. 2008).

Other research strived towards an alternative explanation of use emphasizing that “utilization can often be assumed and have argued that performance impacts will result from Task-Technology Fit that is, when a technology provides features and support that “fit” the requirements of a task” (Goodhue and Thompson 1995, p.214). Indeed, Task-Technology Fit (TTF) highlights the linkage between user task needs and the available functionality of the IT. However, here again, literature expressed the shortcomings of the model, drawing on mixed approaches combining TAM and TTF (Dishaw and Strong 1999) or pointing out model weaknesses in world wide web environment as “many issues remain unresolved, and many questions remain unanswered” (D’Ambra and Wilson 2004, p.306).

2.1.2 Social Behaviors in the course of System Usage: the Need for Re-Conceptualizing Technology Usage

These aforementioned theories have been questioned for a matter of parsimonious model formation with poor specification of users' needs and objectives in a multifaceted and partial context (Delone 2003; Bokhari 2005). As a result, the variables system usage and user satisfaction have been extensively studied, but seldom with the relationship established between each one (Mawhinney 1990):

“The most commonly used measures of IS success are “system usage” and “user satisfaction”, though it is rare that both are used simultaneously to evaluate the same system. However various studies have attempted to explore the relationship between system usage and user satisfaction but the findings about this relationship are mixed. Some studies show zero or negative correlation while others found a positive correlation between system usage and user satisfaction” (Bokhari 2005, p.212)

Given the above, scholars urge the academic world to revisit the concept of system usage in nomological contexts with structure and function formularizing:

“The structure of system usage is tripartite, comprising a user, system, and task, and researchers need to justify which elements of usage are most relevant for their study. In terms of function, researchers should choose measures for each element (i.e., user, system, and/or task) that tie closely to the other constructs in the researcher's nomological network” (Burton-Jones and Straub 2006, p. 226; Straub and Burton-Jones 2007).

The re-conceptualization work has been performed in past research, such as the IS acceptance model (Straub et al. 1995; Venkatesh et al. 2003), where social and cognitive variables add to the determination of behavior using TRA (Theory of Reasoned Action) (Fishbein and Ajzen 1975) and TPB (Theory of Planned Behavior) (Ajzen 1991). However this step forward lacks two clarifications:

- “• There is no accepted definition of the system usage construct in the IS literature,
- There is no accepted approach for selecting the relevant content of usage for any given study context” (Burton-Jones and Straub 2006, p.231).

Further criticism can be directed towards system usage due to its high focus on technology and too weak attention on social behaviors (Lee 2000), especially when system usage leads to online collective action where users become social actors. Social mechanisms that will be influenced or twisted by the medium used ought to be taken into account in the specific context of the online action. Indeed, each contributor's conduct will add to the social and psychological climate from which action will draw and fuel its performance (Sonnentag and Frese 2002) and the lack of comprehension of collective usages (Burton-Jones and Gallivan 2007) will prevent one from understanding the groundings of virtual communities and collective action.

2.1.3 Users as Social Actors

Integrating social behavior in our conceptualizations of system usage underlies a social actor approach of the '*system user*'. This is why Lamb and Kling (2003) also appeal for a reconceptualization of the user – “the active agent in information system use”, as a social actor, pointing out that:

“the theories that shape this understanding and influence the design and use of ICTs rely primarily on cognitive social psychology and cybernetic models that are contextually underdeveloped leaving nearly all of the organizational and environmental context outside the model”, p.198.

Therefore, users' comprehension needs further in-depth analysis, considering the cognitive processes system usage may require and social dynamics they are faced with (Orlikowski 1992).

Drawing upon the aforementioned lack of in-depth understanding of system usage (Delone 2003) and Morgeson and Hofmann (1999) studies, Burton-Jones and Gallivan (2007) investigated the 'multilevel nature of system usage or collectives usages of information systems, highlighting “the fundamental difference between individual and collective phenomena”, p.663:

“Individual ability allows individuals to receive, process, and respond to information in the external environment. It is perhaps self-evident that teams and organizations are also able to receive, interpret, and process information.... In all cases, the effects or outputs are responses to external stimuli. Given the observation of these responses, we make inferences regarding the entities' ability.

Clearly, however, the structure of this ability changes when moving from individuals to some larger collective. The structure of individual ability refers to scripts, schema, and other cognitive and biological factors, whereas the structure of ability for higher level aggregates not only includes these cognitive and biological factors (since collectives are composed of individuals), but they also involve something more. This something more is the interaction between these individuals” (Hofmann 2002).

Reflecting on the parallel that can be set up following this statement, Burton-Jones and Gallivan (2007) posited: “Collective usage is not simply the sum of its parts (i.e., the sum of members' usage) because it also comprises interactions”, p.663.

Going beyond this notion of interdependencies-in-use, they developed a multilevel theory of system usage, namely system usage constructed in a multilevel fashion, where levels are individual, group and organization and dimensions are function of usage, structure of usage and context of usage. Structure of usage is comprised of two sub-dimensions, interdependencies-in-use and form of collective use:

“Because we wish to focus on interactions that are inexorably part of collective usage, rather than general social or task-related interactions, we focus on interdependencies-in-use, that is, dependencies among members of a collective that relate to their use of a system. Accordingly, we suggest that the first step in determining whether collective usage exists is to identify the presence of interdependencies-in-use”, (Burton-Jones and Gallivan 2007, p.663).

Therefore we identify in this regard a critical research gap, as collective usage needs to take into account social value such as interdependencies-in-use, as a founding value and major discriminator of separate individuals' use that does not strictly apply in group, organization and even less in Web 2.0 environments.

In a different way, but aiming at addressing similar gaps, researchers have been interested in applying other social theories in order to get a better understanding of individual and collective use (DeSanctis and Poole 1994; Orlikowski 1992), "because technologies are socially constructed, they can be reconstructed as well. ... The technology itself can be changed by those using it" (Mohrman and Lawler 1984, p.136). And, in this respect, these works draw on other aspects that differentiate from TAM and UTAUT approaches, offering venue for further research, highlighting system collective usages comprehension and social rules and dynamics depending on the context . Finally, Web 2.0 changes considerably the scope of system usage from its multilevel standpoint and a holistic view of concepts and models should be required in order to investigate Web 2.0 adoption (Usluel and Mazman 2009), including the aforementioned theories TRA (Fishbein and Ajzen 1975), TPB (Ajzen 1991), TAM (Davis 1989), UTAUT (Venkatesh et al. 2003) and their revisions (Venkatesh 2000; Burton-Jones and Straub 2006) as well as MGB (Perugini and Bagozzi 2001), which adds the notion of emotions. We will be further investigating this concept in order to respond to these research questions, as literature lacks knowledge to address these matters.

2.2 Web 2.0 Attributes

The Web 2.0 concept is not only empowered by new IT usages, it is also intimately linked to a critical mass of users that will drive IT adoption and online collective action. Web 2.0 differentiates from Web 1.0 by the notion of collective interaction empowered by new technologies, where social computing, user-generated content and software as a service form the DNA of this new Internet generation. Information and tools allow real-time collective innovation enriched by innovations and new applications that constantly appear in a never-ending process and reflect the innate properties of this socially embedded concept:

“Web 2.0 is much more than just pasting a new user interface onto an old application. It’s a way of thinking, a new perspective on the entire business of software—from concept through delivery, from marketing through support. Web 2.0 thrives on network effects: databases that get richer the more people interact with them, applications that are smarter the more people use them, marketing that is driven by user stories and experiences, and applications that interact with each other to form a broader computing platform.” (Musser and O’Reilly 2006, p.3)

Consequently, Internet use has dramatically expanded over the last years and virtual communities are blossoming on the World Wide Web. As a result and despite the signal-to-noise ratio that is inevitably growing with more than 2 billion human-beings connected throughout the globe (Nielson Online, 2012) , even if “online interaction is relatively anonymous, that there is no central authority, and that it is difficult or

impossible to impose monetary or physical sanctions on someone, it is striking that the Internet is not literally a war of all against all” (Smith and Kollock 1999, p.220).

Web 2.0 implacably unearths the wisdom of crowds and collective intelligence thanks to this critical mass of users and expands on virtual communities driven by the gift economy phenomenon (Rheingold 1995), that will be further explained below.

2.2.1 Characteristics of Computer-Mediated-Communication

Since its inception, there has been growing interest in computer-mediated communication (CMC) and its effects on interpersonal behaviors. However, the results do not voice the same conclusions, depending on the context or methodology (Walther 1995). They can vary to absolute opposite results; some studies highlighted the impersonal, task-oriented and hostile characteristic of this form of communication; other studies highlighted the creation of warm personal relations with adjustments in interpersonal relations over time.

2.2.1.1 Attributes of Face-to-Face Communication

Face-to-Face (FtF) is the richest form of communication and according to the Media Richness Theory (Daft and Lengel 1986) it has four attributes:

- “i) the capacity for providing immediate feedback (synchronicity);
- ii) the number of social cues (i.e. verbal, non-verbal, and visual) available;
- iii) the ability to personalize individual messages;
- iv) the ability to express ideas with natural language” (Chan 2011, p. 85).

FtF allows communicators to get indications of meaning behind the words through non-verbal communication which weighs for “about two-thirds of all communication between two people or between one speaker and a group of listeners” (Hogan and Stubbs 2003, p.121). One cannot not communicate (Watzlawick et al. 1972), whether it is through body language, facial expression, tone of voice or consistency of nonverbal and verbal communication.

2.2.1.2 Attributes of CMC

The opposite of the FtF communication medium, CMC is the lowest medium of communication in the social context. It carries no nonverbal visual or auditory cues and inhibits the nature of social context decoding that can lead to more equivocal exchanges, the feedback may be delayed and the most current cues are text-based. The latter could seem surprising as the technology allows live video feed, but, against all odds, this hasn't been adopted and people prefer to communicate through text messages (Schiffrin et al. 2010).

Drawing on those aspects and despite the absence of “rich” communication characteristics, studies demonstrated the advantages of CMC compared to FtF. Firstly, one get time to prepare and think about what will be sent. Secondly, one can concentrate on the content itself, with no concern for social appropriateness and one's own nonverbal formalities or others nonverbal decoding. These attributes can enhance significantly verbal communication of individuals suffering from shyness or any other fear or reluctance of FtF interactions (Chan 2011), foster relationship development, positive affect and well-being (Boneva et al. 2006; Tidwell and Walther 2002), enhance

connectedness and greater productivity (Sproull and Kiesler 1992; Finholt and Sproull 1990).

Furthermore, greater productivity is expressed on Web 2.0 by UGC (User Generated Content), which has gained momentum over the years and can be depicted as follows:

“When Time designated ‘you’ as Person of the Year 2006, the editors paid tribute to the millions of anonymous web users who dedicate their creative energy to a booming web culture. The cover story heralded the many volunteers filling so-called user-generated content (UGC) platforms. After decades of vilifying the passive couch potato, the press now venerates the active participant in digital culture” (Van Dijck 2009, p.41)

2.2.2 *Computer-Mediated-Communication in Health 2.0 Context*

Associated with the notions of: Web 2.0/technology, patients, healthcare professionals, social networking, health information/content, collaboration, and change of healthcare system (Van De Belt et al. 2010), Health 2.0 is derived from the term Web 2.0, the concept of the interactive web, where everyone is offered an opportunity to communicate, share information and experiences with new Internet technologies.

Among those, online patients’ communities offer numerous possibilities to Patients 2.0 – aka ePatients - for sharing experiences, socializing, getting peer support, breaking isolation, increasing self-disclosure through anonymity (Bargh et al. 2002; Joinson 2001), as people do in other virtual communities (Mercklé 2004) but where common interests are health-related (Orizio et al. 2010). In spite of these recent developments, research is still scarce about how those patients interact over the web, about how

collective action emerges through the use of health communities by ePatients.

Furthermore, the determinants of patients' online commitment remain un-studied.

In "Patients 2.0" we include people who use information and communication to interact with others on health issues (Bos et al. 2008). A 2010 study based on a sample of adult individuals in the United States shows that about 80% of the population connect to the Internet to learn about health related topics, 34% read comments from other Internet users, and 18% of the persons studied research carried out by persons sharing similar pathologies (Pew Internet). In France, over the same period, 64% of patients were seeking information on health (Ipsos polling Institute 2010).

In the context of Health 2.0, White and Dorman (2001) highlighted benefits as well as disadvantages of CMC supporting patients' need to interact.

Benefits are manifold and priceless added-value resources for patients' everyday hardship:

- i) Overcoming isolation allowed by asynchronous communication accessible 24/7/365 on demand respecting a patient's time required to respond, as well as erasing geographical barriers,
- ii) Anonymity, allowing patients to discuss sensitive issues as well as sidestepping the disclosure of socio demographic factors such as age, gender, racial or ethnic identity, income, social status or disabilities,
- iii) Nonverbal cues are eliminated for the sake of enhanced privacy,
- iv) Wisdom of crowds, due to the "unlimited" number of participants, permits group members to draw from a wide variety of perspectives, experiences, disabilities and points of view,

- v) Increased influence in advocacy capacity and a means of organizing and networking politically for a particular cause or disease.

Despite the above, disadvantages are also multiple:

- i) Digital divide effect, that eliminates from participation the world's poor population or those without a rudimentary knowledge of how to use a keyboard and computer,
- ii) Time-consuming effect, while browsing through the extensive amount of information,
- iii) Misinterpretation, an inconvenience of the absence of nonverbal cues,
- iv) Anonymity can be a concern, due to the relative impersonal nature of the medium as well as deceiving behavior that can occur under the cloak of anonymity,
- v) Inaccurate medical information, that can happen when medical advice is given by people without medical training or expertise,
- vi) Addiction, with online relationships replacing gradually real-life social interactions.

To conclude, several aspects of Computer-Mediated support groups for individuals with health-related issues may obviously give rise to concern, but they also provide a valuable “mutual aid and self-help for individuals facing chronic disease, life threatening illness and dependency issues. The benefits of support groups have been widely reported and

include: positive changes in symptoms, enhanced recovery and adaptive responses to the diagnosis of illness, improved quality of life, improved decision” (Coulson 2005, P.580)

2.3 Health 2.0 and the Online Collective Action Phenomenon

Since the spectacular adoption of the Internet, the aspects of online communication on health issues have changed the landscape of medical practice. Until then, medical practice was limited to top-down approaches where health professionals and third parties involved were those communicating information to patients. Only a limited amount of information was delivered in a one way manner or unidirectional way. Together with online 2.0 tools, the health communication paradigm is dramatically changing and many-to-many approaches are gaining momentum, opening wide connected spaces characterized by collaboration and a willingness to help other patients, namely online collective action. As a result, the Audience switches from a passive to an active way of functioning and individuals connect with others with the same disease and share information about symptoms and treatments, along with thoughts about their decision-making processes for the sake of public health.

Yet, revealing health-related matters may not be the easiest thing to do, as the related information is very sensitive, including employment decisions (Heeney et al. 2011) and privacy protection (California Healthcare Foundation 2010). Nevertheless, against all odds, patients are quite inclined to talk about these issues. The 2012 survey from PwC - *Social Media "Likes" Healthcare: From marketing to social business* - reports that one-third of the 1,060 U.S. adults questioned use social web for health discussions, “at any hour of the day with someone in the house next door or halfway across the globe”. The

progression is rising at a rapid pace, from 5% of all adults in 2005 using social networking sites, to half of all adults (50%) in 2011.

“Health social networks are likely to become an important entity of influence in the medicine of the future, as they are generated bottom-up rather than top-down, by those who make medicine exist, namely, patients” (Orizio et al. 2010, p.6).

Together, those insights offer contrasting perspectives on the advantages and risks of engaging in online patients’ communities. For these reasons, the challenge of understanding the determinants of online collective action is crucial for public health. Further, arguably, the use of online patients’ communities will grow over time. It should also probably be encouraged as the sociological, economic and scientific outcomes should help to tackle the ageing population’s health challenges. It helps to find cures for diseases and provides support to patients (Wicks et al. 2010) (Lieberman 2007).

The 2012 survey from PwC - *Social Media "Likes" Healthcare: From marketing to social business* – reports consumers’ specific behaviors, highlighting that “42% of consumers have used social media to access health-related consumer reviews (e.g. of treatments or physicians). Nearly 30% have supported a health cause, 25% have posted about their health experience, and 20% have joined a health forum or community.”

As mentioned above, the literature and surveys offer some preliminary responses about what drives this peer to peer connection. However, the following questions relating to in-depth understanding of patients’ state of mind and intrinsic senses and feelings, addressed by our research, remained unanswered. Are there social and individual values that motivate users to connect online with other patients? What can possibly demotivate

them to engage in virtual communities? Are there social factors involved in the patients' connection process?

The system usage as explained in TAM (Davis 1989) and UTAUT (Venkatesh et al. 2003) do not capture the emotional dimension of online collective action and the concepts and impacts of computer-mediated-communication social cues (Sproull and Kiesler 1986, Chidambaram and Jones 1993). There is no consensus highlighted in the literature concerning the influences of the technology as a medium of collective action. Walther (1995, 1992) argues the positive outcomes of CMC compared to FtF meetings. However, the context of such studies appeared to be determinants to raise conclusions (Walther et al. 2010, Yates and Orlikowski 1992). For online communities addressing the sensitive matters of disease, these background factors ought to be examined cautiously.

2.4 Online Collective Action in Health 2.0: Assets and Drawbacks

It has been proven that Health 2.0 discussions barely suffer from misinformation, especially since corrections may be reported as rapidly as within five hours (Esquivel et al. 2006). Thus, patients 2.0 may get an improved quality of life by connecting on virtual communities for the many benefits provided. This virtual communication allows them for example, to maintain a continuous link with the community members (24/7). They are therefore no longer forced to wait between appointments with their practitioners to be informed about aspects of their daily life, to be reassured about their symptoms or to wait for actions to be taken. It also allows them to find their own rhythm in the Internet asynchronous mode. This allows them to accommodate conversations to their needs and to relieve their anguish at any time of the day or night.

The overall approach and the proliferation of testimonies allow patients to expand significantly their perspectives and feedback. This is also the case for information about rare diseases, whereby those platforms offer important advantages on very specific issues.

However, patients' online collective action also carries its risks. Among them, for example, the danger of wrong medical information being propagated among the Internet users. Furthermore, while mostly absent, a scrupulous control of potential erroneous information should be mandatory to avoid these pitfalls (Culver et al. 1997).

This study's theoretical background and method aim at answering these questions.

Firstly, patients' typologies will be investigated through preliminary interviews with web and medical specialists. Secondly, Field Theory, EVT, gift concepts and MGB, will advise our interview's guide concerning patients' desire to participate in online conversations and the social facts induced by this involvement.

3 - GROUP DYNAMICS AND COLLECTIVE ACTION IN ONLINE CONTEXTS

3 GROUP DYNAMICS AND COLLECTIVE ACTION IN ONLINE CONTEXTS

The literature review provided us with an extensive perspective and understanding of academic primary issues of online collective action and its determinants. Together with a more empirical approach, we integrated the key concepts and studies surrounding our field of inquiry.

The work on the literature review allowed us to: i) gain a retrospective overview of key and (contiguous concepts in the literature independently of the academic fields; ii) choose the relevant approaches, studies, models and constructs from different areas; iii) identify calls and venues for future research, as well as research gaps pertinent to our field of inquiry; iv) inspire the study framework during the empirical data collection; v) find safeguards in relation to findings, results, limitations, future research and conclusion.

The literature review is organized as follows: i) understanding the group and online group dynamics; ii) the key concepts of collective action; iii) the key concepts of online collective action, leveraging gift concepts; iv) the driving and restraining forces of online collective action; v) the background factors of online collective action.

Before quoting the growing IS literature on IT use and related motives which are linked to our purpose, we explore philosophical and psychological literature to advise the

fundamentals of group dynamics, collective action, and their associated field forces in the context of patients' online communities to guide our choices for categorizations.

The backdrop of our theoretical research draws from Lewin's work (1947; 1939) that captures individual conduct and social behavior, and their related implications on social change. Combined with Eccles et al. (1983) Expectancy-Value Theory (EVT) categorizations that will be presented in a section below, these underlying frameworks will allow us to draft a first model of patients' online collective action that will guide us through the field investigation.

After investigation of the structure, the functioning and interest of patients reaching virtual communities, as well as members' profiles, we identified these interdependent field forces in patients' virtual spaces in order to understand their motives for online action and cast values and categorizations of the same field forces.

3.1 Group Definition

Johnson and Johnson (2008) defined a group by people embracing one or more of the following statements: "A small group may be defined as two or more individuals who (a) interact with each other, (b) are interdependent, (c) define themselves and are defined by others as belonging to the group, (d) share norms concerning matters of common interest and participate in a system of interlocking roles, (e) influence each other, (f) find the group rewarding, and (g) pursue common goals." Therefore, the community is either defined by external or internal criteria (Tajfel 1982). External criteria are the outside designations and internal criteria are the group identification. External criteria, as laws

that human-beings have to comply with or adapt and which will influence their behavior and perceptions, have been studied by Lewin (1947) in the Field Theory. We will further describe these concepts in the section below, as it forms the theoretical framework of our research.

In the virtual context, Dholakia et al. (2004) follow Kelman's (1958) approach that will be further explained in the sections below, but, first of all, the notions of field forces need to be illustrated.

3.2 Group Dynamics

Lewin's work on group research focused on various themes such as group structure, group dynamics, social change, constancy and resistance to change and field forces. Indeed, Lewin (1947) argues that: "certain aspects of behavior can be directly related to the resultant force" and "we are able at present to determine psychological component forces only under special conditions", p.15.

Since then, the terminology "group dynamics" has been used to relate dynamic interdependence as a label covering dynamical group properties where properties are defined as types of reactions or types of influences representing certain types of interdependence. These concepts studied by Lewin's field forces in a social psychology experiment aim at explaining social behavior (Lewin 1939).

3.3 Field Forces and Human Behavior

Lewin (1939) explains that human behavior is influenced, from childhood, by social facts and social relations. This allows him to distinguish warm from unfriendly conduct and to divide social attitudes accordingly.

Therefore, any goal setting will scrutinize social facts and the characteristics of a given situation to anticipate the level of success of a particular action. This level will influence and justify his related inspiration. Indeed:

“The level of aspiration is greatly influenced by such social facts as the presence or absence of other persons or by the competitive or noncompetitive character of the situation. It has been shown, too, that the goal-setting depends upon certain ideal goals” (Lewin 1939, p.869).

This theory constitutes a significant contribution to social psychology and provides a conceptual framework, comprising driving forces and restraining forces that picture “the direction and strength of the tendency to change” (Lewin 1946, p.349).

Elie-Dit-Cosaque et al. (2011) also drew on social change theory and the above-mentioned Lewin concepts, in the context of IT usage, highlighting the distinction between “the driving that leads to locomotion” and “the restraining forces referring to the physical or social obstacles that may hinder locomotion”, p.206. However, this study doesn't address the purposes of collective action.

In summary, this purposive behavior, which reminds us of MGB principles (Perugini and Bagozzi 2001), allows us to adopt a practical approach spurred by the Lewin's field-

theoretical account. In this respect, the following sections will concentrate on the identification of “the driving forces” and “the restraining forces” of online collective action, once the contextual background has been clearly outlined.

3.4 Integrating Computer-Mediated-Communication in Group

Dynamics: Online Group Dynamics

3.4.1 Online Group Definition

Online social networks and virtual communities often share the same meaning in the literature. However, Dholakia et al. (2004) differentiated between the two concepts, defining virtual communities as “consumer groups of varying sizes that communicate regularly and for some duration in an organized way over the Internet through a common location or mechanism to achieve personal as well as shared goals of their members”, p.241-242. On the other hand, Ellison and Boyd (2007) argued that social network sites “are primarily organized around people, not interests... structured as personal (or egocentric) networks, with the individual at the center of their own community”, p.219.

The size of the network is a major factor of these two ways of functioning. Indeed, online social networks gather a broad audience enabling users to articulate and make visible their social networks, but the opportunity to come into contact with strangers usually is of minor importance (Ellison and Boyd 2007; Grabner-Kräuter 2009). Putnam (2001) argued that weak ties - referring to social networks - imply a bridging behavior between individuals leaving aside emotional support whereas strong ties – referring to virtual

communities - imply a bonding behavior involving a strong emotional support between individuals. Although not of central interest in this section, this argument entices our interest in emotional value construct in the present research. The bonding value is also one characteristic of the gift concepts that will be illustrated below.

Addressing similar factors, Meglino and Korsgaard (2004) argue that “sociality maintains that group members suspend their personal interests in order to ensure their group’s continued existence”, p.947. Nevertheless, although online social networks and virtual communities are often confused in the literature, this concept will not always apply to both online networks. Virtual communities indeed differ from social networks, in particular because common interest is an important prerequisite for gift-giving culture through the Internet medium (Bergquist and Ljungberg 2001).

Therefore, in the context of patients’ networks, the first model described by Dholakia et al. (2004) applies, allowing us to use the terminology of patients’ virtual communities, leaving aside the terminology and characteristics of social networks, that do not directly concern this present study.

Finally, within these virtual communities, one should also consider the differences in the users profiles and their willingness to participate in the group’s mission. Janzik and Raasch (2011) distinguish between: “ (1) Innovators and activists, (2) crowd-followers and tourists and (3) lurkers. The group of innovators and activists leads discussions and forms opinions, and is a fundamental driver of the Online Communities for its survival and advancement. Tourists have a passing interest in the main topic of the Online Communities. Crowd-followers have individual interests differing from the main topic of

the Online Communities and participate in discussions for other reasons e.g., closer social ties. Lurkers participate passively without contributing within the Online Communities”, p.801-802.

3.4.2 Field Forces in an Online Context

It seems that Lewin’s Field Theory hasn’t been used in an online context. However, driving forces that would make online communities successful have been discussed (Toral et al. 2009).

The specificities of the online action of communities’ members have been presented in the above sections, including system usage that changes communication when mediated by computers. And besides the technology that may offer a mixed picture, a well structured website observing the right principles of appeal or navigation will not be sufficient in itself to ensure blooming and active communities (De Souza and Preece 2004).

Referring to virtual communities opposing social networks, as per the aforementioned criteria, the pervasiveness of social facts remains a crucial characteristic:

“This is because online communities should be understood as a social phenomenon that establishes social networks of people with common interests.

Consequently, success of online communities should be determined by social factors” (Toral et al. 2009, p.379).

Therefore, whether communities’ activities are performed offline or online, we will apply the Field Theory of Lewin to constitute the founding principles of this research.

3.5 Collective Action

3.5.1 Collective Action Concept

An understanding of collective action - and intentions that lead to joint actions - needs a command of many different disciplines and especially philosophy (Tuomela and Miller 1988; Searle 1990; Bratman 1993; Miller 2001; Gilbert 2006), psychology and sociology (Tajfel 1981; Van Zomeren et al. 2008) (see Table 1).

In the area of social psychology, Tajfel (1981) described collective actions as “efforts by large numbers of people, who define themselves and are also often defined by others as a group, to solve collectively a problem they feel they have in common”, p. 244. Giguère et al. (2012) highlighted in this definition of collective actions the notion of *collective social identity* (Tajfel and Turner 1979) and *shared problem perception*. In the *collective social identity* concept, Giguère et al. (2012) explained that “stronger identification with a disadvantaged group is associated with a greater will to participate in a variety of actions aimed at protecting or enhancing the group”, p.182. In the *shared problem perception* concept, Giguère et al. (2012) explained that “the traditional beliefs shared by group members may bring them to collectively recognize an event as threatening and worth uniting against”, p.183. Van Zomeren et al. (2008) further demonstrated that perceived injustice, perceived efficacy and social identity affected collective action. The latter is also motivated by the perceived value of the outcome (Giguère and Lalonde 2010; Bandura 1995) “when individuals perceive a valued outcome to result from collective actions, they are more likely to have a favorable attitude toward them and be willing to participate in them” (Giguère et al. 2012; p.183). This perceived value of the outcome is

also posited in the purposive behavior of MGB (Perugini and Bagozzi 2001); the feeling of injustice that bounds patients can be related to their disease. Still, MGB is complementary to the aforementioned concepts as it includes emotion which has not been studied in the collective action literature (Tang 2008). Furthermore, Lewin (1947) outlined the concepts of change and constancy in group life stating that:

“(a) Change and constancy are relative concepts; group life is never without change, merely differences in the amount and type of change exist;

(b) Any formula which states the conditions for change implies the conditions for no-change as limit, and the conditions of constancy can be analyzed only against a background of “potential” change”, p.13.

In the area of sociology, we will leave aside the concept of power behind collective action (Crozier and Friedberg 1977). Indeed, it may apply in organizations where Crozier and Friedberg highlighted power as a daily mechanism of our social existence, but may be less relevant in the context of patients’ online interactions

Therefore, to understand the dynamics of group life, one needs to get information about “desire for and resistance to specific change”- namely, in this study, collective action and the associated social forces.

3.5.2 Collective Action in IT Contexts

Collective action has been discussed in Information Systems literature referring to social theories (Coleman 1994; Fishbein and Ajzen 1975) and social scientists and psychologists’ reasonings (Hardin 1968; Olson 1965; Sweeney 1973; Schelling 2006;

Oliver et al. 1985) to: i) understand the necessary conditions of collective action (Garud and Kumaraswamy 2005), ii) help explain why individuals engaged in a collective action choose not to free-ride (McLure Wasko and Faraj 2005), iii) highlight the importance of public goods arising from collective and alliance-based collaborative work (Monge et al. 1998) .

Social teams and dynamics of knowledge development and its transfer in both “more and less” virtual teams have also been studied, highlighting the assets of virtual work resulting from information technology (Griffith et al. 2003). However, online collective action is lacking contributions in Information Systems literature and social psychology remains the leading area for surveying this issue. Among the major contributions, Bagozzi and Dholakia (2006) defined open source software user communities’ we-intentions as follows:

“Such group intentions are oriented toward shared activity, which requires (1) mutual responsiveness among participants to the intentions and actions of others, (2) collective commitment to the joint activity, and (3) commitment to support others involved in the activity” p.1101.

We will therefore draw on this very concept, highly instigated by Tuomela (1995) and (Tajfel (1978; 1981) (See Table 1) underlying frameworks (Dholakia et al. 2004) to guide our present research with a view to contributing to the development of a first draft design of online collective action. This first design draft will not be set in stone, so it can be shaped by our field study, as per our aforementioned critical realism view for this research. Indeed, Zachariadis et al. stated that:

“there are two sides of knowledge... the transitive and intransitive objects of knowledge. Intransitive objects of knowledge are the ones that don’t depend on human activity. In other words, it is the knowledge of things which are not invented by humans e.g. gravity, death etc. On the other hand, transitive phenomenons are “artificial objects fashioned into items of knowledge by the science of the day” (2010, p.7; Bhaskar 1998).

This “science of the day” will complete theoretical inputs, based on the appropriate context for patients, where the power of giving may be a fundamental incentive to join collective action, where being meaningful for others is more important than any economic reward; where determinants of this altruistic action can be the quest for the sense of self, belonging and ownership (Abma and Baur 2012).

Table 1. Collective Action			
Area	Concept	Definition	Author
Philosophy	We-Intentions	“A commitment of an individual to participate in joint action and involves an implicit or explicit agreement between the participants to engage in that joint action.” (Tuomela 1995, p.2)	(Tuomela 1995)
	Collective Intentionality	“Collective intentionality presupposes a Background sense of the other as a candidate for cooperative agency; that is, it presupposes a sense of others as more than mere conscious agents, indeed as actual or potential members of a cooperative activity.” (Searle 1990, p.414)	(Searle 1990)
	Shared Intention	“We should, instead, understand shared intention, in the basic case, as a state of affairs consisting primarily of appropriate attitudes of each individual participant and their interrelations” (Bratman 1993, p.99)	(Bratman 1993)
	CET (Collective End Theory) of joint action	“Joint actions are a species of interdependent action in which there is little or no conflict; joint actions involve a number of agents performing interdependent actions in order to realise a common goal” (Miller 2001, p.36)	(Miller 2001)
	Joint Commitment	“Collective action is interpreted as a matter of people doing something together, and it is assumed that this involves their having a collective intention to do that thing together... the parties are jointly committed to intend as a body that such-and-such.” (Gilbert 2006, p.3)	(Gilbert 2006)
Social Psychology	Collective Actions	Collective actions are described as “efforts by large numbers of people, who define themselves and are also often defined by others as a group, to solve collectively a problem they feel they have in common” (Tajfel 1981, p. 244)	(Tajfel 1981)
	SIMCA (Social Identity Model of Collective Action)	Van Zomeren et al. (2008) demonstrate that “the key subjective predictors of collective action as well as their interrelationships” are “subjective <i>injustice</i> , <i>identity</i> , and <i>efficacy</i> ”, p.504.	(Van Zomeren et al. 2008)

Sociology	Collective Action	Collective action is studied within organizations where individuals are players and not passive agents who perform instructions. Individuals develop strategies based on personal goals that sometimes disregard the organization's interests.	(Crozier and Friedberg 1977)
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3.6 Online Collective Action

3.6.1 Online Collective Action Concept

Interactions in online communities are based on foundations other than traditional cost-benefit rationality, even though the precise analysis of online collective action dimensions lack description in the literature that may be explained by the fact that online collective action will depend on the virtual community itself, its social identity (Allen and Meyer 1996; Bergami and Bagozzi 2000; Luhtanen and Crocker 1992) and its groups norms (Dholakia et al. 2004) .

But mostly, with a growing interest in the literature with the emergence of open source software development and open source revolution (Bergquist and Ljungberg 2001; Bezroukov 1999; Feller and Fitzgerald 2000; Kollock 1999; Mockus et al. 2000), researchers realized that the functioning of virtual communities relies on gift relationships and the gift economy (Rheingold 1995) which have the potential to frame many online collective actions (Skageby 2010).

3.6.2 Driving and Restraining Forces of Online Collective Action: First Draft Model of Online Collective Action

Guided by Lewin's underlying field forces framework, all these aforementioned interrelated concepts formed the theoretical foundations of this study and raised questions about the categorization of "the driving forces" and "the restraining forces" (Lewin 1947) of online collective action, their benefits and the associated background factors. However, considering the lack of information in the context of patients 2.0, we paid close attention to the understandings brought by the field, and to the determinants of this online collective action that will be exclusive to the medical domain.

As a result, as explained above and elaborated below, we focus on the driving forces of the value of online collective action – namely social, utilitarian and hedonic values of EVT (Eccles et al. 1983) – and the restraining forces of online collective action – namely cost value of EVT - to establish the design of our critical realism research (Zachariadis et al. 2010). These insights helped us outline a first draft model of driving and restraining forces of online collective action that we will further shape by exploring the field and the literature (see Figure 1). We aimed at observing an iterative and constant oscillation, allowing a continuous movement between theoretical knowledge and practical knowledge. This draft model is designed to be completed by grounded inputs in respect to the literature underlying framework.

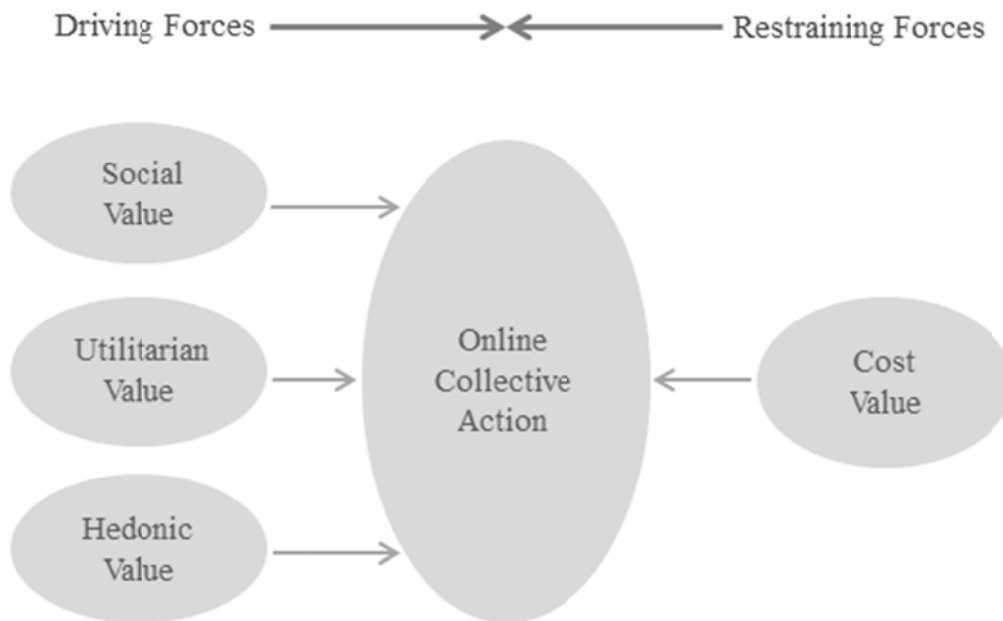


Figure 1 First Draft Design of Model of Driving and Restraining Forces of Online Collective Action

These four values were inspired by the Expectancy-Value Theory (EVT) (Eccles et al. 1983), which outlined the four components of task-value and can be defined as follows.

The first component, social value, draws upon attainment value also related to self-schema and identity theories (Markus and Wurf 1987) and referring to the relevance of engaging in a task for one's self-schema volition to respect or disrespect (Eccles and Wigfield 2002). It also includes "the personal importance of doing well on a task" (Eccles and Wigfield 2002, p.119; Eccles et al. 1983). In virtual environments, Dholakia et al. (2004) defined it as a means to "understand and deepen salient aspects of one's self through social interactions" (p.144).

The second component, utilitarian value, "is determined by how well a task relates to current and future goals... A task can have positive value to a person because it facilitates important future goals" (Eccles and Wigfield 2002, p.120).

The third component, hedonic value, draws upon 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, p.120). It is also a determinant for participation in virtual communities (Dholakia et al. 2004).

The fourth component, cost value, is conceptualized in terms of the negative aspects of engaging in the task” (Eccles and Wigfield 2002, p.120). 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).

Following those insights, the present research draws on the functioning of groups through social influence and social identity, leveraging the gift concepts and exploring the role of positive emotions in behavioral action. All these concepts were brought by the literature but influenced, from the very start of this research, by our field experience as well as during the interview process.

4 – RESEARCH DESIGN AND METHODS

4 RESEARCH DESIGN AND METHODS

In this research, we used a partially grounded, qualitative methodology consistent with our exploratory quest to understand the determinants of online collective action for patients, as shown in Table 2. Our research follows the tradition of qualitative methods in information systems (IS) (Trauth 2001). The search for direct contact, close listening, dialogue and open conversation with patients and stakeholders motivated our exploratory qualitative research design in order to better understand this recent social phenomenon, such as engaging in virtual communities (Alan Branthwaite and Simon Patterson 2011). We used semi-structured interviews (Roussel and Wacheux 2005), which were conducted taking into account the potential difficulties of qualitative interviews, namely: elite bias, Hawthorne effects (Parsons 1974) and construction of knowledge for our main concerns (Myers and Newman 2007).

Our motivations to use such interviews were multiple. Firstly, given the nascent stream of research, we had the feeling that the existing theoretical framework was deficient in too many categories and that the existing theoretical framework had to be adapted to the selected field of inquiry. Secondly, we were further expecting that some constructs regarding determinants of online collective action could potentially emerge from the patients' experiences. Thirdly, we were convinced that our specific field of inquiry required this partly inductive approach. Hence, this method was expected to contribute to *i*) the content validity for the constructs in the subsequent quantitative part and to *ii*) enrich the conceptual framework, which is grounded in both theory and actual human thoughts.

Accordingly, research interviews were conducted in France with Doctors and caregivers, Health 2.0 and Web 2.0 experts, patients and patients' relatives as shown in Table 2 below. Patients were members of a breast cancer community, and parents of autistic children. The interviewees were mostly female and all were adults. These interviews offered primary information about individual driving forces for online collective action. It also helped us to identify the most relevant determinants of online collaborative agency to be included in the research model.

Approach	Objectives	Procedures
Qualitative Approach	<ul style="list-style-type: none"> • Identify the specificities of patients that join virtual communities. • Contextualizing the variables chosen for the research model and survey instrument; ensuring content validity. • Identifying in practice the emerging individual and social determinants of patients joining web-based patients' virtual communities. • Examining the role played by the IT artifacts versus information and emotional needs in patient's commitment. 	<ul style="list-style-type: none"> • Ethnographic research approach in order to gain preliminary insights on patients' sociological typology as well as driving and restraining forces for online collective action. • 25 preliminary semi-structured interviews with Doctors and caregivers, Health 2.0 experts and Web 2.0 experts, users of patients' social networks. • 29 subsequent interviews conducted with participants who had to deal with their own health issues or that of relatives.

The steps that have been followed are explained in the Figure 2 below:

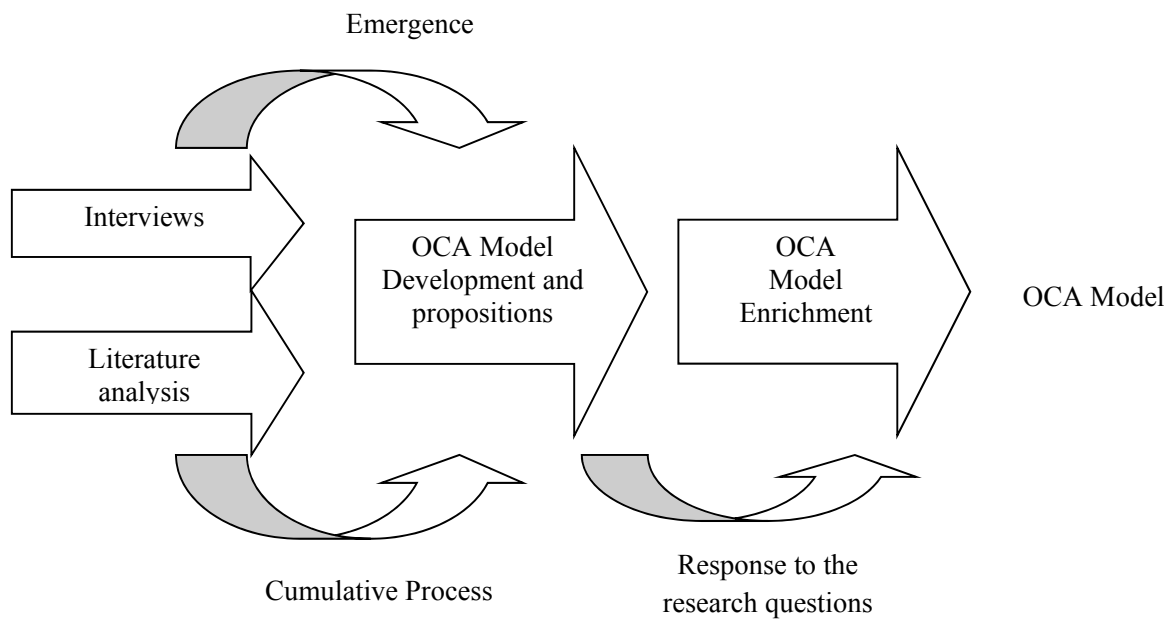


Figure 2 Critical Realism Research Design

4.1 Semi-Structured Interviews

Interviews are frequently used in qualitative research for gathering individuals' experiences and perspectives (Bryman and Bell 2011; Roussel and Wacheux 2005). Targeting the right panel allows the researchers to appropriately document the study, and provide rich insights from the field as the interviewees are welcome to speak freely under confidentiality agreements. In order to mitigate the way data collection and interpretation activities could affect both the researcher and the interviewee (Klein and Myers 1999) we chose to conduct semi-structured interviews. These added rigor and consistency across interviews to the data collection (Myers 2013), "where the researcher urges the respondent to communicate many, detailed and quality information on topics

related to the research, with limited influences that guarantee the absence of bias and serve a good scientificity” (Roussel and Wacheux 2005, p.102).

The interview guides (see Figure 4, 5) that will be further described in the following sections) assisted in the facilitation of the interviews (McCracken 1988). They were constructed in compliance with DeMarrais (2004)’s guidelines suggesting to alternate short and clear questions, questions that would allow participants to recall specific event and few open-ended questions. These questions were designed based upon our literature review and our field knowledge.

4.2 Research Field

Healthcare professionals’ preliminary interviews enabled us to separate patients 2.0 in groups that would be the potential target of our study. Indeed, it would have been unrealistic to expect to meet the demand of patients on the Internet without making a cautious identification of these populations. The very condition of the patient will influence his/her need for information sharing and exchange between people affected by the same disease. Thus, the desires of interaction between patients on sporadic concerns are fundamentally different from the concerns of patients with acute or chronic disease (PwC 2012). Patients’ families are also facing problems in their own daily lives and are interested to hear the feedback from others involved in similar difficulties. Our panel was therefore restricted to patients affected by chronic and serious diseases and patients with rare diseases and their families.

The breast cancer community studied is one of the very first French virtual communities that came out of an isolated initiative and has no real economic model, except fundraising. The social network, founded in 2002, is a nonprofit association and thus operates through donations and is maintained in this manner. The virtual community displays, as a first feature, the forum where women exchange comments about their daily fight against breast cancer. The site has now over 10,000 registered patients. The platform is open and can be read without registration, which leaves the choice to any member either to show complete transparency about her personal information or to keep anonymity.

The rare disease community for patients' relatives studied is a closed Facebook group created in 2010 and issued from an independent platform that decided to use Facebook's services to reduce its operational costs. Only patients' relatives, who are parents of autistic children and have been co-opted by a group member, are allowed to join this closed virtual space that includes around 100 persons. A moderator is present, is active and performs in a positive manner in order to inspire an uplifting mood within the group, despite the difficult testimonies from parents talking about their children's sickness.

4.3 Research Participants

As shown in Table 3, we use an ethnographic research approach in order to get preliminary insights into patients' sociological typology as well as driving and restraining forces for online collective action. We conducted preliminary interviews with Doctors and caregivers (5 persons), Health 2.0 experts (13 persons) and Web 2.0 experts (7

persons). Of the 25 persons interviewed for these preliminary interviews, 11 were female and 14 were male. All preliminary interviewees were “connected” people, i.e. social media users. Health 2.0 experts were social media users specialized in the healthcare arena. Considering their presence and activities on the different connected platforms, I could identify their knowledge on the research issue by the frequency and content they posted online. The virtual communities’ choices were consequently deduced by interviewees’ guidance as well as the size and longevity of the entities.

One should note that 54 codings were conducted on 37 different persons. Indeed, among the 25 preliminary interviewees, 17 persons were actually patients themselves or patients’ relatives. As a result and from these preliminary interviews, we collected insights concerning the panel’s choice to be surveyed including the selection, when appropriate, of preliminary interviewees as well.

Table 3. Interviews		
Interviewees	#	Purpose
Doctors and caregivers	5	To increase our understanding of the feelings and concerns of the patient population from a medical standpoint.
Health 2.0 experts	13	To increase our understanding of the patient population's driving and restraining forces for joining Health 2.0 IT from a medical and technological standpoint.
Web 2.0 experts	7	To increase our understanding of an individual's driving and restraining forces for joining online communities. To establish contrasts between health communities and more traditional communities.
Patients	21	To contextualize the individual and social determinants for joining virtual communities from a patient standpoint.
Patients' relatives	8	To find the individual and social determinants for joining virtual communities from the standpoint of patients' relatives.
<i>Total</i>		<u>54</u>

The main reason for conducting these introductory interviews was our lack of knowledge about which patient category to address. Doctors, caregivers, Health 2.0 experts and Web 2.0 experts appeared to have the knowledge that would unearth the insights we were looking for. Indeed, it would have been unrealistic to expect to understand the patients' demands on the Internet without making a cautious segmentation of this population, which was the introductory question of our interview guide as shown in Table 4.

Table 4. Interview Guide in Preliminary SDCI	
Questions	Objectives
Is there an existing patient typology for a focus group whether they gather online or offline?	To identify a patient panel to address for the study
Are there patients' networks that are more suitable for some patients than other	To identify a patient's panel that would not be relevant for the study
What would be the patients' motives for online engagement?	To compare the feedback of experts about determinants for patients' online engagement against the literature
What would be some hindrances to engagement?	To compare the feedback of experts about hindrances to patients' online engagement against the literature
What about privacy and data protection?	To compare the feedback of experts about hindrances for patients' online engagement against the literature
Do you think these portals help patients during the healing process?	To compare the feedback of experts about positive psychology and patients' online engagement against the literature

Therefore, these preliminary investigations gave us insights into which categories of patients to be interview, including both sociological typology and predominant factor guidelines that our study was concerned with. Some testimonies reassured us of the need to address specific categories of virtual communities:

“Virtual communities are probably not for all patients, but they are particularly suitable for two categories of patients: chronic patients and patients suffering from rare diseases. They also cater to families. The greatest proof of the usefulness of virtual communities for health matters lies in the categorization.”

“The sites are especially suitable for chronic diseases. And patients need to be informed ... I do think that one is informed when a chronic patient, when one has a rare disease he may know it better than his doctor.”

“In the selection of virtual communities I would give priority to the chronic or rare diseases. And I think that the networks in connection with rare or orphan diseases are among the most dynamic, one feels the need to find good information and share it with other patients.”

As mentioned above, patients' families are also involved in the problems of everyday life experienced by their loved ones and are conscious of the crucial importance of the feedback coming from others with similar problems (PwC 2012).

Hence, we focused on patients with chronic diseases, severe diseases and patients' relatives and proceeded, as shown in Table 5, to interview patients (21 persons) and patients relatives (8 persons), irrespective of whether they were willing or reluctant to join these virtual spaces. Also we included in our panel patients who were reluctant to join online communities, we questioned women engaged in a breast cancer community and relatives of autistic children engaged in a rare disease community. Out of the 29 patients, 25 females and 4 males were interviewed.

Table 5. Interview Guide in Patients and Patients' Relatives SDCI	
Questions	Value's Dimension Addressed
Do you feel the need to be informed on your disease?	Information Needs
Where do you go to find medical information?	Inaccurate Medical Information
Do you think online medical information is relevant?	
What (other than information) would you seek on an online medical portal?	Instrumental Needs, Positive Emotions, Belongingness Needs, Exclusive Value, Overcoming Isolation
Would you say special relations are developed with other patients participating?	Belongingness Needs, Group Norms
Do you trust online medical portal participants?	
Do you feel the need to be connected to other online patients?	
Do you mind your testimonies being exposed online?	Privacy Protection
How do you feel when you're connected to people living the same pathologies?	Positive Emotions, Negative Emotions
Do you feel pleasure while connected to these participants?	
Do you think you're helping people while connected?	Giving-Help
Do you feel your participation in the debate useful?	Other emergent dimensions
What would be the ideal patients' community?	
Is it easy to find what you are looking for on the patients' virtual community web site?	
Is the patients' virtual community web site attractive?	

4.4 Coding and Analysis Sequencing Perspective: Critical Realism Paradigm

We used qualitative data analysis software (NVivo9 and then NVivo10) to proceed to the thematic coding and data mapping (Bazeley and Jackson 2013).

The aim of interview coding was to highlight the relevance of presumed levels of values' dimensions of online collective action harnessed from the literature and interviewees' day-to-day experiences of virtual communities. Hence, we expected unknown or new categories to emerge from interviewees' accounts.

Once we had gleaned enough material and semantic saturation was reached – i.e. when the last of our 54 interviews' coding didn't make any further category emerge and, as a result, minimal incremental learning (Glaser and Strauss 1967) -, we conducted our data analysis in two steps. First and before coding the data obtained in interviews, we set broad directives to the presumed categories as explained above. The initial dictionary of categories was drawn from the literature study resulting in 14 a priori themes (See § 6.2 and Annex 2). Second and as an ongoing process we created categories from the data itself and tried to establish coherent links between all these categories that could change the assumptions of current theories. The method fulfilled the obligations of theory and data comparison beginning with data collection. It emphasized an incremental approach to data gathering, as, throughout the transcripts' analysis and coding process, new categories were added when related to our study issues. "A key to this process is to consider a broad range of literature" (Eisenhardt 1989, p.544). This first coding process ended up in a dictionary of themes comprising 28 themes (See Annex 3). This was done in light of our goal to follow the critical realism paradigm (Zachariadis et al. 2010; Mingers 2000), implying that since, in this 2.0's research, "IS is conducted within social

organizations, social science is also of relevance” (Mingers 2004, p.91). Mingers (2004) further argues on this philosophical position stating that “critical realism asserts that the conditions for knowledge do not arise in our minds but in the structure of reality, and that such knowledge will not be universal and ahistorical”, p.92.

Therefore, aware of intransitive objects of knowledge – namely non-human-invented-, our work in the field was intended to discover the transitive dimension of knowledge helped by social sciences’ theories and their potential human-invented alterations (Bhaskar 2010). In this regard Mingers states that:

“This distinction allows us to admit the epistemic relativity of science, the fact that knowledge is always historically and socially located, without losing the ontological dimension” (2004, p.299).

Indeed, the categories list and its principal theme were inspired from related literature, but we changed this list during the course of the interviews following this critical realism theoretical framework (See § 6.3 and Annex 3). Thus, in this research, through an exploratory process and analysis of the production of concepts by social actors in real settings and specific fields of inquiry- i.e, transitive dimension of knowledge - we sought theoretical emergence, based on how well data either fit or shape conceptual categories we identified from the literature, in iterative back and forth work between the research field and literature.

5 – MODEL FORMULATION AND PROPOSITIONS

5 MODEL FORMULATION AND PROPOSITIONS

Following Lewin (1947) and Eccles et al. (1983) theories, we have built on a first draft model of driving and restraining forces of online collective action (See Figure 1), influenced by the Dholakia et al. (2004) work in an online context, itself inspired by MGB (Perugini and Bagozzi 2001). Although this model does not respond to the complete understanding of online collective action phenomenon in Health 2.0 environments, it values a synthetic framework of this construct and its field forces. Indeed, none of these models thoroughly covered all aspects of what would drive patients to join online virtual communities and participate in communal work. In order to ensure a more comprehensive perspective of the patients' online collective action phenomenon, this research seeks clarification and further information from both literature and field. Therefore, constantly attentive to both sources, we revisited the literature accordingly and enriched the model subsequently.

Following the chronology of our findings, this section is organized as outlined below.

Firstly, as part of the driving forces of online collective action and driven by repeated patients' feedback on emerging concepts – namely: “the need to help”, “the need to give back” - we inquire further into the gift concepts' theories.

Then, we address each construct of driving forces enumerated by Eccles et al. (1983) EVT – namely: social, utilitarian and hedonic values – applied to online contexts, in search of existing and new concepts.

So, we listened to patients' testimonies concerning IT artifacts and the notions of habits and consulted the relevant literature.

Thereafter, we address EVT construct of restraining forces – namely cost value – applied to online contexts, in search of existing and new concepts.

Finally, we completed our model with every sub-dimension gathered by this constant to-and-from between the literature and patients' testimonies.

5.1 Driving Forces of Online Collective Action

5.1.1 Gift Concepts: Social Value

5.1.1.1 Leveraging Gift Concepts

The concepts of gift have been broadly developed in the literature (see Table 6.1, 6.2).

Gift-giving concepts highlight “the connection between giver and receiver is the inescapable backdrop within which a gift-giving experience must be examined” (Larsen and Watson 2001, p. 894). They are closely related to the strength of ties (Granovetter 1983).

Mauss (2002), through ethnographic studies of primitive societies, defined gift as the action, from a representative of the community, to give by offering something valuable to someone in order to seal a relationship in a mutual indebtedness. Therefore, the gift, through its specificities, embodies the power that compels the recipient to give back, in a utilitarian perspective.

Malinowski (2010) stressed the notion of bond created, especially between individuals, thanks to these gift-giving experiences. Although critics argue that some goods create “a political dependency on inalienable possessions” (Weiner 1992, p.39) drawing on the

“paradox of keeping while giving”, we believe that these specific cases don’t contradict the Mauss and Malinowski general notion of reciprocity as the implicit and core ingredient of a sustainable relation offered by the gift-giving experience. We will also exclude Derrida's comprehension stating that "for there to be a gift, there must be no reciprocity, return, exchange, counter-gift, or debt" (1992, p.12), as it argues the issue of "semantic precomprehension" rather than the action itself.

More recent studies highlighted the four dimensions of the gift-giving experience (Larsen and Watson 2001) essentially serving as “signals of a person’s intentions about future investment in a relationship” (Camerer 1988, p.180). Firstly, the gift-giving experience is comprised of an economic value where “participants do not give gifts out of altruism, but rather because they expect to receive something at a later date” (Larsen and Watson 2001, p.891). This dimension disputes the concept of pure gifts, where seen as “the logical opposite of commodity exchange and necessarily personal, reciprocal, and socially binding” (Laidlaw 2000, p.618). This dimension may also conflict with the emotionally-loaded intangible aspect, conveyed by the meaning the gift discloses over the tangible object per se (Chakrabarti and Berthon 2012). Secondly, the gift-giving experience involves a functional value (Sheth et al. 1991), where gifts’ utilitarian performance remains the driver of the individuals’ perception of the value of gifts. However functional value is often of minor relevance in gift-giving experiences (Larsen and Watson 2001), and one should not mistake the utilitarian performance of the gift itself for the utilitarian perspective designed by the giver as highlighted above and in Table 6.1, in Mauss and Malinowski’s definition of the gift. Thirdly, the gift-giving experience encompasses a social value, symbolizing and conveying meaning (Camerer

1988), indebtedness and social ties and where “gift exchange is an exchange of inalienable objects between people who are in a state of reciprocal dependence that establishes a qualitative relationship between the transactors” (Gregory 1982, p.101). Fourthly, the gift-giving experience entails an expressive value as the expression of the giver’s self is contained by the gift as a recipient of donor’s self-identity (Sherry et al. 1993) as “giving one is giving oneself” (Mauss 2002, p.59) and “to make a gift of something to someone is to make a present of some part of oneself” (Mauss 2002, p.16).

Although this aforementioned framework ought to be applied to online environments and health-related communities, the state of literature, in this respect, may inspire us in terms of values to be taken into account, namely: functional value, social value and social identity construct.

Table 6.1 Gift Concepts as an Utilitarian Value

Dimension	Area	Definition	Author	Implication for Online Collective Action
Utilitarian Value	Sociology	“If one gives things and returns them, it is because one is giving and returning ‘respects’—we still say ‘courtesies’. Yet it is also because by giving one is giving <i>oneself</i> , and if one gives <i>oneself</i> , it is because one ‘owes’ <i>oneself</i> —one’s person and one’s goods—to others.” (Mauss 2002, p.59)	(Mauss 2002)	Giving consists in taking the initiative in the exchange that seals a relationship in a mutual indebtedness. Reciprocity is an implicit and essential condition of the gift-giving experience that will induce the quality and sustainability of collective action
	Anthropology	Malinowski (2010) emphasized the reciprocity of exchanges as the demonstration of gratitude between individuals. Gratitude ensures the duration and stability of the trade and its repetition secures the implication of both parts.	(Malinowski 2010)	
	Sociology	“Gift exchange is an exchange of <i>inalienable</i> objects between people who are in a state of reciprocal <i>dependence</i> that establishes a <i>qualitative</i> relationship between the <i>transactors</i> ” (Gregory 1982, p.16)	(Gregory 1982)	
	Anthropology	In Bataille's theory of consumption, the accursed share is that excessive and non-recuperable part of the economy which highlights the willingness to create a link, to sacrifice something to manifest the desire to create this link.	(Bataille 1967)	
	Sociology	Free gift doesn't exist and altruistic behavior in gift-giving is a missing characteristic. Reciprocal behavior is a core incentive of the gift-giving experience.	(Godbout and Caillé 1992)	
	Sociology	“The variety of sociological explanations for gift giving suggests a second explanation, that gifts might serve multiple signaling purposes simultaneously – signaling “willingness” to invest in a relationship while also conveying meaning about the giver’s tastes or identity or beliefs about receivers” (Camerer 1988, p.199)	(Camerer 1988)	

Table 6.2 Gift Concepts as a Social Value

Dimension	Area	Definition	Author	Implication for Online Collective Action
Social Value	Anthropology and Psychology	“If we take the synthetic power of gifts, which establish and maintain the bonds of affection between friends, lovers, and comrades, and if we add to these a circulation wider than binary give-and-take, we shall soon derive society, or at least those societies – family, guilt, fraternity, sorority, band, community – that cohere through faithfulness and gratitude. While gifts are marked by motion and momentum at the level of the individual, gift exchange at the level of the group offers equilibrium and coherence, a kind of anarchist stability.” (Hyde 2007, p.96)	(Hyde 2007)	
	Media and Communication	“Gift economies are potent systems for eliciting and developing behaviors that the market cannot — sharing, collaboration, honor, trust, sociability, loyalty. In this capacity, gift economies are an important force in creating wealth, both the material kind prized by the market and the social and spiritual kind needed by any happy, integrated human being.” (Bollier 2001, p.3)	(Bollier 2001)	Giving, whether considered as self-centered or other-oriented, when present in a community context creates a dynamic that leads to a sharing spirit supporting online collective action
	Media and Communication	“Gift economies can indeed support individual selfish motivation and needs, but, when pursued by a larger number of people, converge to form common resources or positive externalities that create a ‘sharing spirit’ that is different from the pure utilitarian rationalism of economic theory” (Skageby 2010, p.172)	(Skageby 2010)	

5.1.1.2 Online Gift-Giving Experiences

When gift-giving experiences as classically defined occur on the Internet, they encounter background discrepancies in settings. For example, the recipient of useful information may be operating under anonymity and never be met again. Therefore a balanced reciprocity performed on a one-to-one basis loses significance and momentum, and the gifts are conducted for the benefit of the group as a whole. This network-wide accounting system (Smith and Kollock 1999) that allows the giver to receive back from another actor of the system introduces the concept of generalized reciprocity (Skageby 2010), which remains unknown or hardly conceivable in real life and offline exchanges. As a result, online gift-giving experiences foster higher generosity, as the giver does not have the guarantee of immediate reciprocation and faces the risk of free-riding behavior that can end up in social dilemmas (Kollock 1998, Yamagishi and Cook 1993, Kollock 1993).

Literature and research demonstrate that patients, confined in virtual worlds, “gift-give” differently, with regard to the first two dimensions above, namely:

- i) although not similar to pure gifts (White and Dorman 2001) their virtual behaviors don't embed an economic value, due to the context itself of their actions,
- ii) while “it is less common for the functionality of a product to be central in gift exchanges” (Larsen and Watson 2001, p.893), patients perform peer-to-peer healthcare; “lending a hand, lending an ear, lending advice”. Pew Internet research showed that “one in five internet users have gone online to find others who might have health concerns similar to theirs” (Pew Internet 2011).

Other dimensions of the concept can be featured. However, one should be cautious opposing the anti-utilitarian (“showcasing the rationales of personal relations and altruistic behavior for gift-giving”) and the utilitarian views (“highlight the rationales of the market, i.e. profit, trade, and exchange for gift giving”) (Chakrabarti and Berthon 2012) as the first view, referring to pure gift or free gift (Laidlaw 2000), embeds implicit conditions that can rarely be explained or met.

Coming back to virtual context, studies drawing on the power of gift in order to understand the functioning of virtual communities question the social dimension in which “gift giving on the internet gets its social meaning” (Bergquist and Ljungberg 2001, p. 314). The literature highlighted three main characteristics of the gift concepts: i) other-orientation, i.e. helping others in order to enhance their well-being without hidden agenda the ii) bonding value, i.e. developing social relationships, and iii) generalized reciprocity, already mentioned above, when the exchange of goods or services create mutual satisfaction and strengthen the community bonds (Skageby 2010).

Zooming in on patients’ virtual communities, their functioning relies on gifts as a way of:

- i) offering support without demand of a return (other-orientation),
- ii) creating solid social relationships whose foundations are composed of the sharing of dedicated and health-related information generating the group social identity (Tajfel, 1982) (bonding value),
- iii) allowing flows of information and social exchange of different kinds, which constitute the very purposes of the groups and representing its norms, namely

reciprocity of actions within the community (Bratman 1999) (generalized reciprocity) (see Table 7).

As a result, the concept of other-orientation, among other highly relevant gifts' dimensions, unearths a relevant attribute in the context of communities of patients that needs to be further explored in our study.

Table 7 Online Gift Concepts as Utilitarian, Social and Hedonic Values

Dimension	Relevant Facet	Definition	Author	Implication for Online Collective Action
Social, Utilitarian and Hedonic Values	Giving-Help (Other-Orientation)	Draws on the concept of gift, implying a notion of pleasure related with the act of giving and independently of any hidden agenda that would seal a relationship of mutual indebtedness (Alter 2010; Mauss 2000), this dimension is motivated by the idea of pleasure behind the help given by patients to other patients.	(Alter 2010; Mauss 2000)	
	Giving-Help (Bonding Value)	“For gift-exchange is not only the significant form in which archaic societies reproduce themselves; giving and taking are also the elementary activities through which sociability became rich in evolutionary chances, and upon which a community-building process still rests.” (Berking 1999, p.31)	(Berking 1999)	Giving, whether considered as other-orientation self-characteristic, bonding or reciprocal instruments, foster online collective action
	Giving-Help (Generalized Reciprocity)	“Reciprocity is often the means and vector of mutual self-interest” (Gérard-Varet and Kolm 2000, p.2) “Perspective assumes that the giver expects something in return” (Skageby 2010)	(Gérard-Varet and Kolm; Skageby 2010)	

5.1.1.3 Gift Concepts Transitive Knowledge from Patients' Perspective

Considering the aforementioned literature inputs (See Table 7), our main concern was to remain exhaustive in our research investigation to the largest extent possible. But what has been most striking after the first interviews and throughout the entire interviewing process, observing the required distance from the researcher standpoint, is the frequent lack of a hidden agenda on the part of patients, as illustrated by Mauss (2000: Alter 2010).

Patients certainly join online virtual communities for bonding reasons and to get helped, but most testimonies were also showing the underlying willingness to help others without ensuring a return for the help given:

“Yes. This is extremely important in these communities. Because you become the one who helps. You help because you wish to do so, you need it, just like that. It is often one-sided because you can do it and it's important for you to do so just for what it means.” (Breast cancer community patient)

Therefore, in our draft model action (see Figure 1), as the notion of giving-help was frequently described and actually performed, we decided to add under the social value category, the giving-help dimension. We expect our study to further investigate this value in the case of patients' virtual action in online communities as this description supplements the operating model of groups described by Dholakia et al. (2004), which does not mention this notion of gift-giving and this categorization meets the literature outcomes on gifting concepts (see Table 6.1, 6.2, 7).

Therefore:

Proposition 1: Giving-Help is positively related to online action regarding virtual patients' communities.

(Social Value of Online Collective Action's Driving Forces)

5.1.2 Social Values

Pursuant to the already mentioned three components of task-value of Eccles et al. (1983) that may spur online collective action, we will seek, helped by both field and literature review in our critical realism research design, what concepts and dimensions they may refer to for online users and especially patients connected on virtual communities. These components are comprised of social, utilitarian and hedonic values.

5.1.2.1 Functioning of Groups through Social Influence: Introducing Social Identity and Group Norms

The Gift concepts are very similar to those of social influence, especially when addressing virtual communities' issues. In the context of patients' communities, we find it relevant to explore social influence literature about the driving forces for online collective action and to complete it with the other-orientation concept embedded in gift-giving theories.

Dholakia et al. (2004), drawing on Kelman's (1958) perceptions of interpersonal influences, categorize social influence's variables for online participants. The latter are comprised of social identity and group norms' constructs, observing that face-to-face social context cues differ with media communication (Sproull and Kiesler 1986).

Compliance, the Kelman's third variable of social influence, has been left behind by Dholakia et al., being considered of minor importance in the case of online communities. Indeed, participants do not feel the need to conform to the online group, expecting rewards or fearing punishment, as the possibility to leave the virtual engagement can easily be done, as the feeling of freedom is high.

5.1.2.2 Identification or Social Identity

Social identity comprises the psychological and sociological aspects of individuals' conducts in a group entity embracing three components that explain social cognition and behavior. Group identification or social identity requires: i) cognitive component (awareness of membership), ii) evaluative component (value connotations), iii) emotional component (as an investment).

For patients 2.0 as for members of non-patient groups, social identity refers to a strong sentiment of group belongingness comprised of an affective commitment (Bergami and Bagozzi 2000), a self-awareness of community membership (Ashforth and Mael 1989) and a self-worth evaluation as group member (Dholakia et al. 2004). As chosen by Dholakia et al., in terms of terminology development, we will adopt the term belongingness needs. Therefore:

Proposition 2: Belongingness Needs is positively related to online action regarding virtual patients' communities.

(Social Value of Online Collective Action's Driving Forces)

5.1.2.3 Group Norms or Internalization

In collective or shared intention, participants' attitudes need consistency in order to face reasoning and coherence towards collective planning and future shared activity (Bratman 1999). Collective intention - aka we-intentions - implies commitment and agreement to joint-activity from each protagonist (Tuomela 1995). Dholakia et al. (2004) include these aspects in their model of group norms related to Kelman's concept of internalization, when an individual accepts influence from others towards a behavior because it is congruent with his/her value system (Kelman 1958).

Drawing on Tajfel (1982) theories, - illustrating common interest, interlocking roles, influencing each other, and shared goals- Postmes et al. (2000) investigated the formation of group norms in CMC, positing that group norms have to be understood as emergent properties of the group that organize behavior and that "social and normative context has a substantial impact on CMC use", p.366.

We will further study this CMC use in the following section in the "IT artifacts" paragraph, but first, the aforementioned points allow us to state that in the context of patients' communities:

Proposition 3: Group Norms is positively related to online action regarding virtual patients' communities.

(Social Value of Online Collective Action's Driving Forces)

5.1.2.4 Exclusive Value Transitive Knowledge from Patients' Perspective

To our knowledge, absent from the literature addressing determinants of online action, we however identified the notion of exclusive value. Exclusive value would be referring to Baumeister and Leary's approach on interactions stating that:

“Interactions with a constantly changing sequence of partners will be less satisfactory than repeated interactions with the same person(s), and relatedness without frequent contact will also be unsatisfactory” (1995, p.497).

Indeed, many patients were arguing about their need to interact with exclusive partners, meaning with those that share the same disease, in the case of patients' communities, because:

“When the site is dedicated to a specific category of patients, if I may say so, they have a stronger relationship; there is a very important community effect tenfold ...” (Breast cancer community patient)

Therefore:

Proposition 4: Exclusive Value is positively related to online action regarding virtual patients' communities.

(Social Value of Online Collective Action's Driving Forces)

5.1.3 Utilitarian Values

5.1.3.1 Purposive Value: Information Needs and Instrumental Needs

The notion of information, nurturing and occasionally flooding virtual spaces has often been covered in the above sections.

Besides, information needs and instrumental needs have raised significant interest in Dholakia et al.'s (2004) research as well as in previous studies (Bagozzi and Dholakia 1999). Gathering these two concepts under a single denomination purposive value, Dholakia et al. defined it as follows:

“the value derived from accomplishing some pre-determined instrumental purpose (including giving or receiving information)” through virtual community participation”, (2004, p.244).

Unquestionably of relevance in the context of patients' communities, according to patients' testimonies, we however suggest to keep the two concepts separate for a better understanding of patients' functioning. Therefore:

Proposition 5: Information Needs is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

Proposition 6: Instrumental Needs is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

5.1.3.2 *Overcoming Isolation Transitive Knowledge from Patients' Perspective*

While online, a real break in patients' isolation occurs, erasing all geographical as well as sociological barriers that could have been created by the stigma of a disease itself (White and Dorman 2001). Obviously, those benefits are different – although complementary – from those they would get from traditional social groups operating in real life and of relevance in the present study:

“I understand the need, the need to exchange. When illness isolates, there is a need to regain a semblance of social life.” (Breast cancer community patient)

Testimonies suggested that virtual communities fill these social needs while decreasing patients' isolation and helping them overcoming the burden of loneliness.

Therefore:

Proposition 7: Overcoming Isolation is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

5.1.4 Hedonic Value

5.1.4.1 *The Role of Positive Emotions in Behavioral Action*

Another dimension that seems to be important in communities of patients relates to the emotions conveyed. As it seemed to be a predominant dimension of online collective action from the patients' standpoint, we conducted an in-depth literature review of the emotions construct and its various aspects.

We will come back to the fundamental of action to explore it. Engaging in collective action supposes first being determined to engage in personal action. Previously, philosophers and researchers emphasized the dynamics of reason and passion for understanding action. Pascal, in 1670, exposed the contradiction between passion and reason (Genet 1983, Pascal 2007, Cottingham 1998). Differently, Descartes, in 1649, postulated on the supremacy of reason over passion (Descartes 1989, Cottingham 1998) while Hume, in 1739, advocated a theory in which reason is governed by passion (Hume 2004) (Beauchamp 2009).

In his model, Hume (2004) asserted that reason does not by itself constitute grounds for an action of volition, and that reason only intervenes to explain passion's impulses to action's proceedings and thus connecting between the two elements. However, Hume also stated that reason cannot oppose passion for directing the will for action:

“Reason is, and ought only to be the slave of the passion, and can never pretend to any other office than to serve and obey them” (2004, p. 375) .

By passion, Hume categorizes the following feelings: i) direct passions (desire, aversion, joy, hope and fear), ii) indirect passions (pride, humility, love, hatred, vanity, envy, pity, malice, esteem, benevolence, respect and compassion).

While exploring other research areas, we found that positive psychology literature highlighted that “positive emotions broaden the scope of attention, cognition and action” (Fredrickson 2004, p. 1369), and “improve psychological well-being, and perhaps also their psychological health” (Fredrickson 2004, p. 1371; 2000). Clinicians, using the benefits of positive psychology with depressed people by questioning their recalling of

events responsible for positive emotions, saw improvements in their condition. Indeed, faster healing but also greater autonomy from the disease is experienced (Rudd et al. 2004) (Laubie 2011).

Therefore, positive emotions contribute to their welfare and its optimal function in the present moment (Diener et al. 1991). Positive emotions also encourage stepping back in the face of upcoming events, avoidance of negative thoughts, emotional resilience and the development of resources in times of trial (Fredrickson 2004). A responsible environment provides further positive emotions to the patients, his/her relatives and other patients 2.0; not only for the immediate satisfaction it provides but also because it endows them with a force that will be of help in future battles and will allow them to find the right resources in a flexible adaptation and virtuous cycle (Fredrickson and Joiner 2002).

Neuropsychological theories further show that cognitive performance is improved by the presence of positive emotions, indicating that positive affect is associated with an increased level of dopamine in the brain, developing the capacity of flexible and creative thought patterns in respect and response to the problems encountered (Ashby et al. 1999, Isen 1987). Positive emotions are also presented in marketing literature, as Dholakia et al. (2004) relate to entertainment value, “derived from fun and relaxation through playing or otherwise interacting with others”, p.244.

Referring to gift concept, Chakrabarti and Berthon (2012) also argued that “in order to understand the total gift-giving experience, researchers should emphasize more on the intangible thoughts and emotions over the tangible object of the gifts per se”, p.155,

referring to the hedonic value of our levels of value of online collective action (see Figure 1) .

5.1.4.2 The Role of Emotions in IS Research

All these studies, from researchers in fields other than IT, urge us to pay thorough attention to emotions in order to better understand patients 2.0 behavior.

In online context, researchers demonstrated that, besides decreased isolation, patients' virtual communities fostered emotional support while interactions and shared experiences (White and Dorman 2001). The CMC offers convenience for collective action and "50% of postings concerned socio- emotional exchanges" (White and Dorman 2001, p.700).

Coming back to IT use, the literature demonstrated the relationship between emotions and IT through intermediate adaptation behaviors (Beaudry and Pinsonneault 2010). However, to our knowledge, prior research didn't address the context of patients' usage of online communities. Therefore, we will further explore the patients' behaviors in the context of virtual communities, drawing on Beaudry and Pinsonneault's statement:

"emotions are a mental state of readiness for action that promote behavioral activation" (2010, p. 690), therefore:

Proposition 8: Positive Emotions is positively related to online action regarding virtual patients' communities.

(Hedonic Value of Online Collective Action's Driving Forces)

5.1.5 IT Artifacts: Utilitarian and Hedonic Values

5.1.5.1 IT Artifacts

User satisfaction, likelihood and frequency of use are valuable online commodities, as Internet users are exposed to so many different choices and are becoming reluctant to noise and time wasting. Indeed, meeting system usage concepts of TAM (Davis 1989), Shackel and Richardson (1991) explained that usability “is not only conceived of as ease of use but also equally involves efficacy i.e., effectiveness in terms of measures of (human) performance”, p.24. However, the question opens a wide field of research with an extensive set of usability and performance measures (Benbunan-Fich 2001, Van Waes 2000, Benbunan-Fich 1999, Fang and Holsapple 2007) considering the variety of online websites categories themselves dedicated to different audiences and purposes.

Phillips and Chapparro (2009) noticed that when users appreciated the visual appearance of a website at first glance, they may continue the browsing experience regardless the website’s usability, and as a result, perceived usability can be more influential on the intention to use than ease of use and efficacy (Kurosu and Kashimura 1995, Brady and Phillips 2003). Other researchers demonstrated that visual appeal influences users rating of perceived usability, sometimes in contradiction with actual usability (Tractinsky et al. 2000).

Therefore, we drew on Nelson et al. (2005) to select navigational structure as a system quality parameter that affects trust in the IT artifact (Vance et al. 2008; Loiacono et al. 2007; Montoya-Weiss et al. 2003; Wolfinbarger and Gilly 2003). Visual appeal has also been widely studied as a website quality dimension (Vance et al. 2008; Loiacono et al.

2007; Tseng and Fogg 1999; Wagner 2005), and together with navigational structure, both these attributes may be leading to attitudes, intentions and ultimately behaviors (Fishbein and Ajzen 1975) (see Table 8).

Table 8. IT Artifacts as Utilitarian and Hedonic Values				
Dimension	Relevant Facet	Definition	Author	Implication for Online Collective Action
Utilitarian Value	Navigational Structure	“Navigational structure is defined as the organization and hierarchical layout of the content and pages in a Website and involves the relative effort required for a user to traverse an IT artifact user interface” (Vance et al. 2008, p.79)	(Vance et al. 2008)	The model including system quality constructs of navigational structure and visual appeal influences positively the intention to use an online platform and possibly to contribute to online collective action
Hedonic Value	Visual Appeal	“Visual appeal is defined as the tangible aspect of the online environment that reflects the ‘look and feel’ or perceived attractiveness of a Website. Visual appeal connotes the attractiveness of the Web site, including graphics, colors, and fonts.” (Vance et al. 2008, p.79)	(Vance et al. 2008)	

5.1.5.2 IT Artifacts Transitive Knowledge from Patients’ Perspective

For the specific population of patients, the usability of e-health web sites as information providers has been studied, examining authority of source, layout and appearance, advertising presence and aspect, readability, etc. (Eysenbach 2002, Curtis 2010, Sillence and Briggs 2007, Sillence et al. 2007). Researchers have been exploring some of these aspects and developed dedicated scales such as the Perceived Health Web Site Usability Questionnaire (PHWSUQ), which includes 25 principles in 4 categories: (1) readability, (2) presentation of information, (3) incorporation of other media, (4) ease of navigation (Nahm et al. 2004). However, research lacks information about health-related virtual

communities and the role of emotions in their rating of perceived usability, with regard to visual appeal that may influence the usability perception of users.

Therefore, we will add to our study the two aforementioned categories – namely navigational structure as a utilitarian value as it refers to “how well a task relates to current and future goals” (Eccles and Wigfield 2002, p.120) and visual appeal as a hedonic value as it refers to “the enjoyment the individual gets from performing the activity” (Eccles and Wigfield 2002, p.120) – in order to help us understand the functioning of Health 2.0 communities.

Proposition 9: Navigational Structure is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

Proposition 10: Visual Appeal is positively related to online action regarding virtual patients' communities.

(Hedonic Value of Online Collective Action's Driving Forces)

5.1.6 Habits

5.1.6.1 On Habits

In TPB, Ajzen (Ajzen 1991) did not subscribe to the view of past behaviors as being meaningful for predicting present ones. For researchers such as Bamberg et al. who stated that: “if social behavior is reasoned, then—it is argued—frequency of prior behavior should have only an indirect link to later behavior; its effect should be

mediated by intention and perceived behavioral control” (2003, p.176), or others such as Sommer (2011): habits would not be a relevant predictor of action according to TPB.

However, many researchers have examined this factor in greater depth (Ouellette and Wood 1998; Aarts et al. 1998; Perugini and Bagozzi 2001). Some specifically expanded the subject to IT use focusing on habits, and found a significant effect of the latter “triggered by environmental cues” (Ortiz de Guinea and Markus 2009, p.440).

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 it deals with IT use, habits refer to habitual behaviors, rather than to behaviors guided by intentions (Limayem and Hirt 2003; Kim and Malhotra 2005). In this regard, goal-directed behaviors differ from intentions in terms of appreciation and consciousness of decision (Ahuja and Thatcher 2005). Indeed, as primary reasons induce action in the concept of intention, goal-directed-behavior theory suggests that goals can be reached without individuals being fully conscious of his or her thoughts. This occurs especially when the goal-directed-behaviors encounter frequent repetitions and thus action is performed in a familiar environment as habits.

Aarts and Dijksterhuis further assert that habits can be considered as links between goals and actions, activated by the environment, and which contributes to reaching these goals through automatic behavior. Therefore, the more often the activation of a goal conducts to the same behavior, the stronger the unconscious processes (Aarts and Dijksterhuis 2000; Heckhausen and Beckmann 1990; Reason 1990).

5.1.6.2 Habits Transitive Knowledge from Patients' Perspective

Concerning patients, the phenomenon of addiction that relates to the development of habits, outlined above, was demonstrated to be of relevance by White and Dorman (2001) in CMC patients' support groups.

We acknowledge that the repeated connection of the patient may lead to the Internet addiction, implying an extensive level of virtual community interactions (Beard and Wolf 2001; Young 2004), and thereby of online collective action (Laubie and Elie-Dit-Cosaque 2012).

However and despite the above mentioned inputs taken from the literature, the automatic nature of this concept questions the relevance of its introduction in our model.

Drawing on Ajzen's (2005) statement about background factors – that will be further explained in a following section – we will include habits in the background factors category, as past experiences that may be related to or influence users' beliefs. Therefore, we will study and code it but put it apart from our research model, namely driving forces of online collective action.

5.2 Restraining Forces of Online Collective Action

In the same perspective and taking into account the above mentioned last component of task-value of Eccles et al. (1983) that may hinder online collective action, we will seek, through the literature review as well as helped by patients' inputs, what concepts and dimensions ought to be included in our model concerning the cost value.

5.2.1 Cost Value

5.2.1.1 The Role of Trust in Behavioral Action

As already described, cost value relates to “negative aspects of engaging in the task” (Eccles and Wigfield 2002).

In online community interactions, many researchers associated the cost value with trust, referring to privacy concerns (Metzger 2004; Dwyer et al. 2007; Dong-Hee 2010; Fogel and Nehmad 2009). On this subject, the press related several users’ unfortunate experiences with personal data disclosure (Read 2006). As Peter Steiner put in the caption to a cartoon: “on the Internet, nobody knows you’re a dog” and from the very beginning of online chat services, the “Joan and Alex” story featured the case of a psychiatrist who pretended to be a young disabled woman (Van Gelder 1991). Some years later “a rape in cyberspace” was depicted (Dibbell 1998) as well as the social networking website Bebo’s privacy issues (Eriksen 2008), Facebook being used by students to mislead campus police (Hass 2006) or Friendster-at-that-time’s new feature: “Who’s Viewed Me” highlighting “Friendster’s own insecurity” (Mintz 2005).

5.2.1.2 Trust Transitive Knowledge from Patients’ Perspective

In the specific context of online patients’ communities (Laubie and Elie-Dit-Cosaque 2012), trust is also an essential dimension of cost.

Indeed, on the Internet, patients will be the very first population concerned about the respect of privacy (Goldberg et al. 1997):

“Yes, I think one must still be wary of Internet. You quickly forget that everything can be seen there that it seems to be a sphere of confidence.” (Breast cancer community patient)

Secondly, the accuracy of information (Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000) will be of significant importance, especially when they interact online with groups of people concerning very personal issues, such as health (Coulson 2005; White and Dorman 2001)::

“The misinformation fear still remains.” (Breast cancer community patient)

Lastly, any negative emotion that can be triggered by online comment could have dreadful impacts, so much so that some patients would prefer leaving these virtual spaces for a period of time or even indefinitely:

“Sometimes we read very difficult stories. It is not clear how to receive it when it's written by people who really write with deep sincerity in distress. When you are not prepared, it's hard to take.” (Breast cancer community patient)

Therefore:

Proposition 11: Negative Emotions are negatively related to online action regarding virtual patients' communities.

(Cost Value of Online Collective Action's Driving Forces)

Proposition 12: Privacy Protection is negatively related to online action regarding virtual patients' communities.

(Cost Value of Online Collective Action's Driving Forces)

Proposition 13: Inaccurate Medical Information is negatively related to online action regarding virtual patients' communities.

(Cost Value of Online Collective Action's Driving Forces)

5.3 Emerging Model of Online Collective Action

All the variables and propositions discussed in the above sections have to be taken into account and considered for further analysis in the emerging model of patient's online collective action (See Figure 3).

After the complete analysis of the interviews and the closing of the coding, some slight changes in the model occurred, that would then be further identified in figure 3.

Indeed, the underlying framework and our research design allowed us to let any new concept emerge during the data collection and analysis process and to identify regularities and demi-regularities pursuant to the design of critical realism research (Zachariadis et al. 2010). Lawson defined demi-regularity as follows:

“A demi regularity ... is precisely a partial event regularity which prima facie indicates occasional, but less than universal, actualization of a mechanism or tendency, over de definite region of space-time” (1998, p.149).

We will follow this thought, even if “Lawson's examples of demi-regularities include cases that are much more conducive to statistical modeling” (Pratschke 2003, p.25). All the more so as Bhaskar (1979) argued that statistical research designs are irrelevant to social sciences as closure of systems can't possibly be achieved in society, but he moderated his adamant statement positing that open systems demi-regularities can encode social mechanisms' patterns.

On demi-regularities and Lawson research process guidance, Bache also states that:

“Lawson admits a role for demi-regularities at two stages in a realist research project. First, demi-regularities have a role in the context of discovery. Demi-regularities help direct the research process and contribute to the generation of hypotheses about causal mechanisms. Second, demi-regularities could have a role in the assessment of causal explanations” (2003, p.14).

Therefore, critical realism allows us, given the specification of our ontological domain, to explain the widest possible range of phenomena and thus enlightens black boxes and reveals emergent dimension (Pratschke 2003).

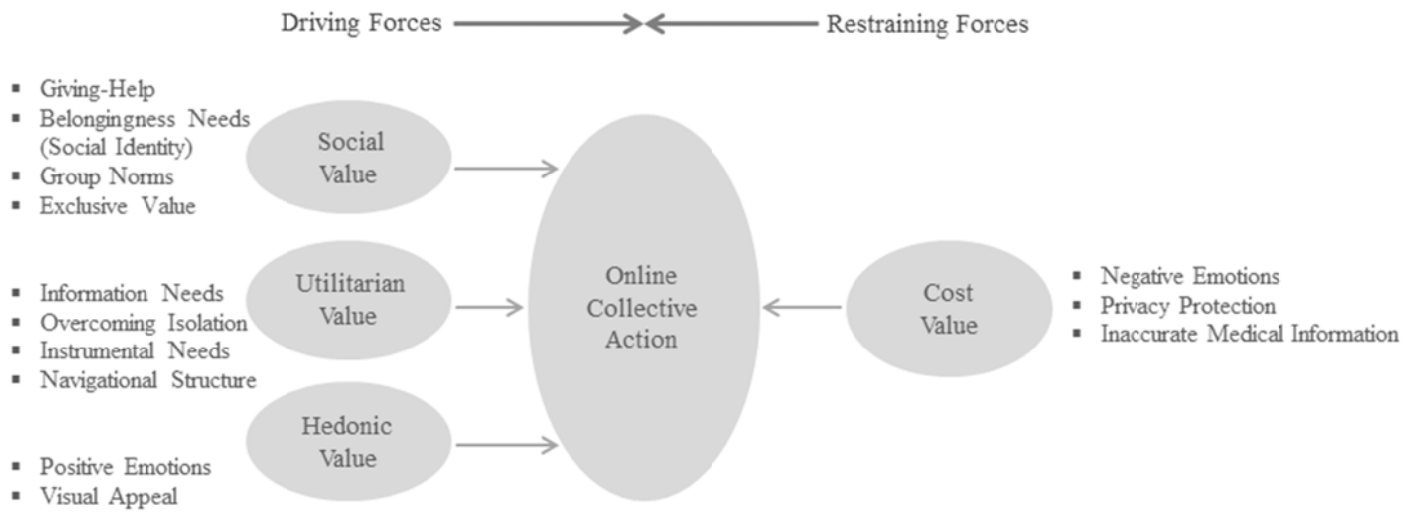


Figure 3 Emerging Model of Driving and Restraining Forces of Online Collective Action (before coding)

6 – MODEL ANALYSIS

6 MODEL ANALYSIS

In this section we argue our research's coding methodology that led to the final dictionary of theme building and the final drawing up of the model.

Through all that work, we kept in mind that researchers agree on what is needed to produce a good qualitative research design: "a skilled activity requiring critical and creative thinking" (Mason 2002, p.46); "a dynamic, intuitive and creative process of inductive reasoning, thinking and theorising" (Basit 2003, p.143).

6.1 Coding Protocol

We used the computer assisted qualitative data analysis software (CAQDAS) NVivo9 and then NVivo10 during the data analysis process throughout this qualitative research, leaving aside manual techniques as:

"proponents of CAQDAS argue that it serves to facilitate an accurate and transparent data analysis process whilst also providing a quick and simple way of counting who said what and when, which in turn, provides a reliable, general picture of the data" (Welsh 2002, p.5; Morison and Moir 1998; Richards and Richards 1994).

Our coding protocol was sketched in six dictionaries of themes knitted together by our emerging model of driving and restraining forces of online collective Action (See Figure 3), namely: i) open codes for driving forces of online collective action (See Table 16.1), ii) open codes for restraining forces of online collective action (See Table 16.2), iii) open codes for online collective action (See Table 17), iv) open codes for background factors of

online collective action (See Table 18), v) open codes for benefits of online collective action (See Table 19).

As a result, driving and restraining forces of online collective action were first classified according to the EVT (Eccles et al. 1983) underlying framework, but also inferred by Dholakia et al. (2004) determinants for participation in virtual communities. The remaining categories were coded to bring contextual information about background factors and benefits of online collective action as a willingness to add rigorousness to the research and to provide possible managerial contributions.

At the beginning of the interviews, we developed an initial list of themes drawn from the literature that allowed us to create the interview guide (See Table 5). During the course of the interviews, new codes and concepts emerged and the list of themes grew accordingly. We explain the choice and in-depth process of his methodology in the paragraphs below.

Mason (2002, p.74), on qualitative research strategy's discussion, outlined three ways of deriving data from interviews: literal, interpretive or reflexive.

Literal reading of interviews derives data "in a literal manner", where attention is focused on literal dialogue and substance, its form and sequence. Interpretive reading of interviews allows the researcher to "read the interviews for what they mean", i.e. draw inference from the content itself.

Reflexive reading of interviews goes beyond the two preceding ways and allows the researcher to read something about his role and his contribution to the data creation and analysis process.

From our critical realism perspective, we chose the interpretive reading manner of our data, not to be confused with purely interpretive approaches where the researcher “not only sees people as primary data source, but seeks their perceptions...the ‘inside view’ rather than imposing an ‘outsider view” (Mason 2002, p.56). Therefore, as critical realism imposes itself “between empiricism and positivism on the one hand and antinaturalism or interpretivism on the other, thus, reinventing a new and more sophisticated version or realist ontology” (Zachariadis et al. 2010, p.4), interpretive reading appeared to offer the right posture for this research. It allowed us to unearth hidden characteristics and to highlight the actual meaning of data. Therefore, we accepted to be involved in constructing a version of what we “think the data mean or represent” and accepted to be engaged in a “reading through or beyond the data in some way, be they texts, artefacts, visual images or whatever” (Mason 2002, p.149).

Besides, our coding was multidimensional, allowing us to apply “multiple codes to the same passage of text” (Saldaña 2012, p.83).

Most of the 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 of the interview material. We coded the interviews after having set broad a priori categories, according to the draft 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, we also allowed for the possible emergence of other categories. In this ongoing coding we hence created new categories drawn from the interviews themselves. This process was repeated three times in order to ensure the nodes' relevance. Recurrent interactions with the research supervisor also ensured the accuracy of the coding process.

6.2 Model Illustration: Categorization Results

Before launching the interviews, the dictionary of a priori themes was comprised of (See Annex 2):

- 8 categories for the driving forces of online collective action (See Table 16.1);
- 2 categories for the restraining forces of online collective action (See Table 16.2);
- 3 categories for online collective action (See Table 17);
- 1 category for the background factors of online collective action (See Table 18);
- No category for benefits of online collective action (See Table 19).

As shown in the second version of the dictionaries of themes (See Annex 3), 5 categories for the driving forces of online collective action (See Table 20.1) and 2 categories for the restraining forces of online collective action (See Table 20.2) emerged from the field through the interview interpretive approach (Mason 2002). Besides, we added the

contextual designation for the 3 categories for online collective action (See Table 21) as well as 3 categories for the benefits (See Table 23) and 4 categories for the background factors of online collective action (See Table 22).

Finally and after the entire coding process and through interview analysis, categories were restructured as follows (Bhaskar 1979) (See Annex 4):

- 5 categories were dropped for the driving forces of online collective action, leaving 8 categories (See Table 24.1);
- 1 category was dropped for the restraining forces of online collective action, leaving 3 categories (See Table 24.2);
- The 3 categories for online collective action were left unchanged (See Table 25);
- 1 category was dropped for the background factors of online collective action (See Table 26);
- The 3 categories for benefits of online collective action were left unchanged (See Table 27).

The following sections explain, for each category, the reasons for the changes introduced.

6.3 Dropped Themes

This section refers to the codes and themes that were dropped. The reason why these concepts were left aside is twofold. Firstly, it was not possible to reconcile these codes with other existing codes. Secondly, the occurrences of associated codes were too few to be taken into account.

6.3.1 Dropped Variables for Driving Forces for Online Collective Action

6.3.1.1 Role of IT Artifacts on Online Collective Action (Navigational Structure and Visual Appeal)

During the interviews with patients' testimonies were more focused on highly-emotionally-loaded feedback than comments on sites' usability. Indeed, patients' empathy, other-orientation volition or bounding values were at the center of concerns. Without these strong expressions of feelings on forums, design or navigational structure won't appeal much to them, as feedback on the positive or neutral role of these two variables were somewhat mitigated (see Table 9). So, although navigation shouldn't be an obstacle to browse fluently on the site, patients reported they paid more attention to what makes the sites warm and welcoming, namely help given by others and especially emotional support as exhibited in Table 12.

Table 9. Categorization of IT Artifacts and Role on Online Collective Action			
Broad Nodes	Role on Online Collective Action	Illustration	Number of References
Navigational Structure	Positive Role	“Yes, the website is fluid and it meets my needs.”*	26
	Neutral Role	“It is not that the site is particularly well thought out, but just I easily get what I’m searching for. Besides I have my habits. Through conversations I easily find what I need.”*	23
Visual Appeal	Positive Role	“The appearance of the website brings to it seriousness and the trust that I will give it. Yes it is important.”*	12
	Neutral Role	“The appearance of the website has little importance compared to the heat or human comfort that I can find through conversations.”*	27

* Quotes from interviews with breast cancer community patients

Indeed, during the course of the interviews, we were particularly interested in comments of patients with a long experience of attending patients’ virtual communities – who happened to frequent them for more than 5 years – highlighting the minor relevance of sites’ visual appeal:

“It is of little importance to me. You know the struggle of the disease will not be relieved by beautiful colors, there is something else in these spaces.” (Breast cancer community patient)

The design is of little importance in the end we are left with the warmth, the emotion conveyed.” (Breast cancer community patient)

However, navigational structure attracted more interest by the same category of patients:

“Yes, in the end the site is simple, easy to navigate and it is important. We should not be embarrassed by the navigation, this is a prerequisite. Some are already anxious about their own request, and what’s more by the technology usage.”

(Breast cancer community patient)

Given the low rate of occurrences reached in the interviews, we won’t keep the navigational structure and visual appeal concepts as driving forces of online collective action, considering them secondary. However, and following this qualitative approach, we recommend and will conduct in a future research study the consolidation of this study by testing these observations and therefore the two aforementioned dimensions in a quantitative analysis.

6.3.1.2 Preference over Medical Process, Doctors Positive Perception and Boredom Avoidance

Preference over Medical Process could be illustrated by:

“This could easily become an automatic behavior compared to making an appointment with a doctor who is not necessarily available before 2-3 months. When you see him, well, you took one hour to go to the hospital. In consultation, you’ve waited 1 more hour and on the top of all that... he does not necessarily have the answer. So there, it is true that the immediate side, effective, with persons you trust, it can be tempting.” (Rare Disease Community patient’s family member)

Doctors Positive Perception could be illustrated by:

“It was during an interview with the surgeon, he recommended the site, thinking it might bring me something.” (Breast cancer community patient)

Boredom Avoidance could be illustrated by:

“At the same time, you're sick and you do not go out, you must do something to avoid boredom.” (Breast cancer community patient)

However, instigated by patients' testimonies, none of these factors appeared to be significant enough to keep them as sub-nodes of driving forces for online collective action. Some patients mentioned these aspects and that's why we highlighted them as emergent categories from the field, but out of the 54 codings, few interviews were neither relating nor confirming these statements. There we decided to drop these values as shown in Annex 4.

6.3.2 Dropped Variables for Restraining Forces for Online Collective Action

6.3.2.1 Complexity of Information

Complexity of Information could be illustrated by:

“But I thought it was complex, patients sometimes become too expert, one can't understand them anymore.” (Breast cancer community patient)

Here again, although it was an interesting testimony, the occurrences were far too few, only rising to 2 (See Table 21.2), to keep this value in our model. We, thus, left this factor aside.

6.3.3 Dropped Variables for Background Factors of Online Collective Action

6.3.3.1 Open Virtual Space

Out of the two communities studied, stances against the opening or the closing of platforms were opposed.

On one hand, it is certainly understandable that parents of autistic children are reluctant to let strangers read the comments posted every day about the evolution of their children's disease. That is the reason why the Facebook group remained closed to public access

On the other hand, it may seem surprising that women facing the hardship of breast cancer are willing to open their platform to strangers – whether they express themselves anonymously or not. Furthermore, when they are asked about such behavior, this question resonates as something that never came to their minds:

"I think it's normal. It is a question I have never thought of. No, for me it is something entirely normal." (Breast cancer community patient)

Due to the few mentions about this factor, the lack and sometimes absence of reflection about it when questioned, and the ethical matters this issue can raise, we decided to drop this category from the results of this research.

6.4 Resulting Model Variables

The below tables 10.1, 10.2 and 11 detail the different facets of the constructs that were identified and kept according to both the whole aforementioned coding process and the inputs of literature.

Table 10.1 Categorization and Leading Concepts - Driving Forces

Broad Nodes	Sub-Nodes	Definition
Driving Forces for Online Collective Action	UV*	Information Needs “The Internet was broken down into various communication and information functions: information retrieval, information giving and conversation.” Therefore, information needs to comprise the following items: “to get information, to learn how to do things, to provide other with information, and to contribute to a pool of information” (Flanagin and Metzger 2001, p.162).
	SV**	Belongingness Needs (Social Identity) "The belongingness hypothesis is that human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships.” (Baumeister and Leary 1995, p.497).
	SV**	Giving Help “For gift-exchange is not only the significant form in which archaic societies reproduce themselves; giving and taking are also the elementary activities through which sociability became rich in evolutionary chances, and upon which ant community-building process still rests.” (Berking 1999, p.31)
	SV**	Exclusive Value “Interactions with a constantly changing sequence of partners will be less satisfactory than repeated interactions with the same person(s), and relatedness without frequent contact will also be unsatisfactory” (Baumeister and Leary 1995, p.497).
	HV***	Positive Emotions “Positive (anticipated) emotions refer to success in achieving a goal” (Perugini and Bagozzi 2001, p.83). In online communities’ contexts, it refers to “fun and relaxation through playing or otherwise interacting with others” (Dholakia et al. 2004, p.244).
	UV*	Overcoming Isolation “With asynchronous communication, participants in online groups have access 24 h a day, 7 days a week, at times most convenient to them” (White and Dorman 2001, p.694).The concept of overcoming isolation refers to the possibility for patients to get an in-demand response for interpersonal relationships.
	SV**	Group Norms Group norms is the concept of people sharing norms concerning matters of common interest and participate in a system of interlocking roles, influencing each other, and pursuing common goals. (Tajfel 1982)
	UV*	Instrumental Needs “When social interactions in online communities help participants to accomplish specific tasks, such as solving problems, validating a decision already reached or buying a product” (Grabner-Kräuter 2010, p.509).

*Utilitarian Value **Social Value ***Hedonic Value

Table 10.2 Categorization and Leading Concepts - Restraining Forces		
Broad Nodes	Sub-Nodes	Definition
Restraining Forces for Online Collective Action	Negative Emotions	“Negative (anticipated) emotions refer to failures in achieving a goal” (Perugini and Bagozzi 2001, p.83). In online communities’ contextual background, it can refer to stress and anxiety through interacting with other patients.
	Privacy Protection	“On the Internet, individuals may trust others to keep private information confidential” (Green 2007, p.44). For health purposes, privacy protection may be of relevance due to patients’ conditions (Goldberg et al. 1997) as well as the privacy policies of health Web sites (Graber et al. 2002).
	Inaccurate Medical Information	“On the Internet, individuals may trust others to provide honest and accurate information” (Green 2007, p.44). In the context of health purposes, there is a risk of dangerous and inaccurate medical information appearing online (Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000)

Table 11. Categorization and Secondary Concepts		
Broad Nodes	Sub-Nodes	Definition
Benefits of Online Collective Action	Belongingness	Patients, upon entering this virtual world, will feel immediately surrounded and supported
	Speed and Strength	
	Enlightened Patients	Virtual communities offer patients valuable knowledge, so much so that they become experts
Background Factors	Role in Healing	Patients claim a positive role on their healing
	Habits	Virtual communities are addictive and affect a population who is imprisoned in idleness and pain.
	Females	More than men, females have the tendency to confide in virtual communities
	Disinhibition	
	Information Control	Patients wish the information gathered online to be moderated
Online Clinical Help Requirement	Patients wish the information gathered online to be moderated by healthcare professionals	

Based on the insights brought by the critical realism approach, the draft and then emerging research models have been enriched and contextualized as exhibited in the figure 4 below.

Furthermore, the content validity of the model-variables has been improved, as we have identified multiple sub-facets of expectancy values with 4 dimensions for social value (group norms, belongingness needs, exclusive value, and giving-help), 3 dimensions for utilitarian value (information needs, instrumental needs, overcoming isolation), and 1 dimension for hedonic value (positive emotions). We have also identified 3 dimensions for cost (inaccuracy of medical information, privacy protection, and negative emotions) and were able to contextualize online collective action.

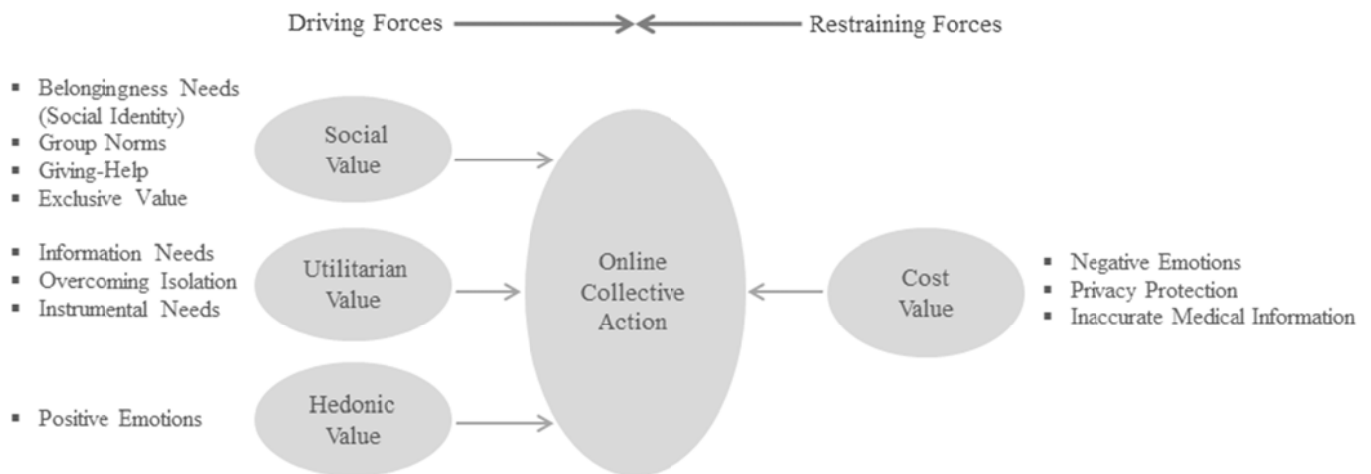


Figure 4 Model of Driving and Restraining Forces of Online Collective Action (after coding)

7 – MODEL RESULTS

7 MODEL RESULTS

Together with the field forces of online collective action, the interviews led to important insights, such as the benefits of online collective action and the categorizations of background factors being as expected and outlined in tables 10.1, 10.2 and 11. Interviews also brought answers about the contextual designation and characteristics of online collective action shown in table 12 below.

Data outlined evidence that Perugini and Bagozzi's model needs adaptation when it comes to patients' communities, as well as Bagozzi and Dholakia's succeeding studies (see Figure 4). The results revealed emerging concepts that are frequently cited by interviewees, such as help-giving that relates to the gift concepts, or exclusive value, i.e. not mixing purposes or common interests of the communities, and thus offering a specific disease forum in the case of patients. Some of these constructs can be explained by the gift-giving concepts that enriched the model. However, some other categories need to be integrated into a dedicated model for patients' engagement in virtual communities to complete existing ones, such as the matter of privacy, or being confronted with inaccurate medical information or negative emotions and, as a result, the cost of engaging in online collective action.

The following sections will present the answers to our research questions; the primary purpose of our present study.

7.1 Research Question 1: Characteristics of Online Collective Action in Patients' Virtual Communities

Drawing on aforementioned Bergquist and Ljungberg's (2001) social meaning concept of gift-giving on the Internet, we investigated what specific designations of the three sub-categories of giving-help – in the context of virtual communities and namely other-orientation, bonding value and generalized reciprocity – may prove to be relevant.

High rate occurrences – as shown in table 12 - highlighted three contextual designations:

i) other-orientation concept relating to the emotional support activity without demand of a return, ii) bonding value concept relating to the information sharing activity about practical advice that will help patients cope with day-to-day health situations, iii) generalized reciprocity concept relating to the flows of general information and social exchange activity, whether it concerns medical knowledge or other purposes.

Other-orientation mainly occurred through the manifestation of emotional support, when patients did care for others with the desire to relieve their suffering and to solace anxieties. The testimonies didn't show any hidden agenda or any expectation of a return. These actions were sufficient for patients to gain social assets and values out of them.

Bonding-value was illustrated by the sharing of one-to-one advices that fitted specific concerns and matched pertinent needs, that were, most of the time, health-related. The very purpose of these actions was to answer utilitarian patients' needs and help them navigate through the hardship they're enduring.

Generalized reciprocity referred to the sharing of one-to-many advices and supports. The very purposes of these exchanges weren't consistently health-related and the concept of hidden agenda absent.

Therefore, results of the categorization of online collective action', as shown in table 12, stressed the importance of emotional support in patients' online interaction.

One should notice that among online collective action's sub-dimensions, other-orientation dimension of giving-help is the most frequently quoted form of interaction. Online communities foster and welcome the discussion of sensitive issues, encouraged by peer support, whether performed under anonymity or not.

Table 12. Categorization of Online Collective Action			
Broad Nodes Generic Designation	Broad Nodes Contextual Designation	Illustration	Number of References
Giving-Help (Other- Orientation)	Emotional Support	“There is so much support in the community. If a person has an anxiety attack in the middle of the night, she can come on the forum and automatically, someone will answer her, because she understands her pain and shares the same feelings.”*	49
Giving-Help (Bonding Value)	About practical advice for coping with day-to-day health situations	“Therefore you understand the importance of being in a community of patients sharing the same disease. We can see how other patients manage everyday problems. There is a lot of advice and help on this.”*	35
Giving-Help (Generalized Reciprocity)	About General Information (Medical or Miscellaneous)	“We asked each other about health topics, we give opinions on practitioners, the good and the less good, the health system, on trials, sometimes on the academic literature. There will always be patients of high expertise to consult in the community.”**	31

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

7.2 Research Question 2: Determinants of Online Collective Action

7.2.1 Driving forces for Online Collective Action

7.2.1.1 Utilitarian Value: Information Needs, Overcoming Isolation, Instrumental Needs

Among all dimensions introduced by the literature and the field, in compliance with our critical realism research design and our interpretive coding approach, information needs was the most cited (see Table 13.1).

Indeed, interviews confirmed the importance of informational needs as a leading factor for patients to engage in virtual communities. For both communities, quality and relevance of advice or flows of information, as well as its ease of understanding, satisfy this need to be informed:

“Yes. In fact, every time I had a question, every time I asked a question, I got the answer.” (Breast cancer community patient)

However, depending of which community was questioned, the incentives for the exchanges were not the same.

For breast cancer patients, motives reside in the information value, but also its immediate access made feasible through the IT tools:

“Between Doctor’s appointments, we have time to get anxious. On the network, we can speak freely whenever we need it.” (Breast cancer community patient)

For the relatives of patients with rare diseases, healthcare professionals may understandably lack answers for the families, due to the lack of scientific and medical knowledge itself. Therefore, virtual communities can represent a unique and important source of information for families:

“When I'm looking for information myself, I reach the Rett syndrome's group. In here, technical information is really at a top level ... when I have a question, I ask my question and I still have girls or guys who will answer me and much better than a practitioner. There is no doubt. What's more, they will respond on all levels to questions practitioners would be unable to answer to.” (Rare Disease Community patient family member)

Virtual communities also offer patients valuable psychological support available on demand that contributes to overcoming their isolation, as well as the restoration of a social life that has often been put on hold due to the disease:

“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, herself, will understand and hear what you say because she experiences the same thing.” (Breast cancer community patient)

Together with the help of other patients' testimonies, problems can be solved and added-value decision making choices can be achieved:

“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.” (Breast cancer community's patient)

Table 13.1 Categorization and Leading Concepts – Utilitarian Value			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Utilitarian Value	Information Needs	“I was looking like so many other people who seek information to know whether what we had was serious or not serious, to know what was my 5-year survival, whether I was going to die within 5 years or not.”*	101
	Overcoming Isolation	“The disease is a social handicap, I am a bit lonely...I really think social networks are perfect. I express there this "me-digital" which is different from "physical self". So you can keep the image you want on the net, either by being someone different or by being yourself.”*	44
	Instrumental Needs	“And then we could ask them a question, no problem. If I have a problem where I can find no answer, I go to them and they often give me the answer.”**	30

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

To conclude, utilitarian value is an important driver for online collective action with information needs taking the lead over any other social or hedonic values. However, social value appeared to bring high incentives for collaborative action according to patients.

7.2.1.2 *Social Value: Belongingness Needs, Group Norms, Giving-Help and Exclusive Value*

When consolidated, social values are the most commented driving forces for online collective action (see Table 13.2). This can't be too surprising considering the social environment surrounding these activities, even when performed online. Besides, this contributes to the very differentiation of virtual communities compared to social networks, proven not to be that socializing (Ellison and Boyd 2007; Grabner-Kräuter 2009).

Belongingness needs conveys a very important motive for online collective action with the second highest number of references. This concept includes the search for similar experience and feedback among the community members due to the sharing of the same pathology's concerns:

“We feel that people support each other. People are willing to help each other, even if we don't know each other well. All of this because we are bound by the same themes and diseases.” (Rare Disease Community patient' family member)

It also discloses important benefits of these communities, that we will describe below, such as the rapid sense of belonging and its strength.

“Because they are human beings and intelligent ones and share the same experience as us. And I feel like this is my family. I feel like these girls are in my living room, and we are talking. And it is really because of this relational we share.” (Breast cancer community patient)

Besides, it reveals patients' need to gather online and to feel that they belong to the group of their peers, mostly experiencing exclusion within their own families, due to the effects of the disease and its physiological consequences, that only other patients can empathize with.

“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.”
(Breast cancer community patient)

Finally, strong ties between online patients highlight the patients' needs to be connected to their networks, in order to share experiences about the course of their illness, even long after their recovery, referring to the need and willingness to give -help:

“So why did I make a blog on that issue after so long time? This is what I am often asked. Because, ultimately, it shouldn't be forgotten. Furthermore, it's because we never forget and because I really wanted to tell myself that I can testify.” (Breast cancer community patient)

So while the patients are in a state of mental and physical distress, the desire to help other patients remains a major cause of commitment in these networks:

“My role is different now, but obviously... I want to give back, and, if possible, to give answers. And often, the girls who subscribe ask us not to disappear, just to know that we're still there, still in remission.” (Breast cancer community patient)

Access to multiple feedback and support groups provide patients with shared anecdotes about their disease. Moreover, interviews showed that, while living difficult time, they do not have the mental availability to listen to stories that are too different from theirs. Indeed, they have the fear of getting lower quality information and they don't want to share their disorders and day-to-day stories with strangers, preferring to exclude patients with other diseases from their platform. We adopted, for this new concept, the exclusive value terminology:

“When it's opened to everyone, as a result, it loses in terms of information. While in our site, we know that we will inevitably connect with sharp people sharing our concerns... and it is very reassuring.” (Breast cancer community patient)

Finally, group norms, the concept of people sharing norms concerning matters of common interest (Tajfel 1982), binds patients and fosters their participation in the online action as well as their long term dedication to the group:

“We realize that we share the same vision with these other women, the same thoughts, perhaps because we share the same problems. This is why we got there, it's mostly why we stayed there.” (Breast cancer community patient)

All these concepts are recalled in table 13.2 and demonstrate the importance of social values and their identified sub-facets as motives for online action.

Table 13.2 Categorization and Leading Concepts – Social Value			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Social Value	Belongingness Needs (Social Identity)	“Because it is reassuring. Because we can meet with other moms going through the same thing. Because you can ask questions that you would not ask to your companion or to your doctor or even to your family, or even to your best friend.”**	94
	Giving Help	“Because it is also to help others, to cheer them up but also to help to solve practical problems ... because I also see, that is to say that there are people who seek me.... It is natural... because, well, I've lived. So if I was in the same situation, I wish someone could help me. This is more in this supporting relationship that I see things...It does not bother me, absolutely not. I could even put on the Internet a very serious condition. As long as it can help others, and even when it can make a difference, give them tips, for me, it is in the public interest.**	67
	Exclusive Value	“When it is more general, you can really get on very distant people concerning the disease. It is a little open to everyone. As a result, the information loses quality. While there, we know that we will inevitably fall on sharp people in the field, in the pathology, and it is very reassuring. So, we spend less time and we know that someone will answer us. We know that this person is concerned, is mostly concerned herself.”**	61
	Group Norms	“I needed people who share my problems, my opinions, my values.”**	31

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

7.2.1.3 Hedonic Value: Positive Emotions

Patients also join these platforms to find emotional assistance to help them overcome the hardship of everyday life. Furthermore, some believe that these emotions help them to live better during their illness, as others think that it may even help them to heal:

“Emotions are present, regularly. In fact, when I'm in low spirits, I go on the network and it goes away.” (Breast cancer community patient)

Far less than expected, in terms of the rate of occurrences in the online collective action's driving force, positive emotions is, nevertheless, an essential value that needs to be taken into account when virtual patients' communities launch and further studied in the academic area (See Table 13.3).

Broad Nodes	Sub-Nodes	Illustration	Number of References
Hedonic Value	Positive Emotions	“Positive emotions! When you see a successful experience, an operation that succeeded, where everything went well, when you feel that parents are pleased that the child did well. Either they post videos, photos or short phrases. Immediately you can feel it. It is palpable. It breathes. This communicates very quickly ... It's fabulous! This is extraordinary. It is magical to live, thousands of kilometers apart, people's emotions and power, at a given instant to be able to feel what they feel and how they share these emotions. I find it very powerful, really, very powerful.”*	61

* Quotes from interviews with breast cancer community patients

7.2.2 Restraining forces for Online Collective Action

The auspicious picture of patients' virtual communities may end with the many negative aspects unearthed by further testimonies highlighting restraining forces for online collective action.

7.2.2.1 Cost Value: Negative Emotions, Inaccurate Medical Information, Privacy Protection

Sometimes, even if patients seek and find information on forums, feedback is too difficult to hear, generating negative emotions that bring on pain:

“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...”

(Breast cancer community patient)

Besides, even if for some patients the struggle to preserve confidentiality is a minor battle compared to the one they face with their illness, privacy protection remains an important issue when interacting online on the daily experiences of their illness:

"In fact, at one point, the shock of news exposes you. Because what you live is very scary, so scary that you're not afraid any longer to give up confidential information." (Breast cancer community patient)

“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”

(Breast cancer community patient)

Finally, another concern may hinder patients' online collective action, namely the fear of receiving inaccurate medical information which would prevent them from returning to the website. Certainly, some patients' expertise is extreme, but not all patients are so enlightened:

“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...” (Breast cancer community patient)

Occurrences of the dimension of cost value proves its high relevancy and a vast room for improvement that would benefit patients' well-being during their online experience (see Table 14).

Table 14 Categorization and Leading Concepts – Cost Value			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Cost Value	Negative Emotions	“Ah, negative emotions.. It’s about anxiety when you compare yourself to people who are in a worse position than you, who are even more afraid than you and who announce their bad news. I mean the person who will have a check-up and comes with a diagnosis of metastases. You take it in the chin because it is your fear that comes back too ... So yes, I’ve already had those damn negative emotions, yes.”*	46
	Privacy Protection	"I think the problem with these social networks is... this sense of security among quotes, but that is not real. And so, people drop out, confide very easily without really measuring the risks. Yes, they reveal a little too much I'd say. Especially, that information can be kept, operated, tested, sorted and segmented. So..."**	33
	Inaccurate Medical Information	“And so it is extremely dangerous, I see when girls exchange information. They found, for example, a new reconstruction technique etc., And when I got interested in information I realized that the reconstruction technique has not been validated, or works in the U.S. but not in France ... but the other girls will say that there is a super reconstruction technique and that it is imperative for them to find the doctor for that, etc.. You see? So I think this kind of invalidated information can be dangerous, yes of course...”**	30

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

7.3 Surrounding constructs of Online Collective Action

Besides the leading concepts questioned and discussed during the course of the interviews, the close listening and open conversations offered us insights about constructs that are worth being disclosed and commented for managerial purposes and contributions.

7.3.1 Benefits of Online Collective Action

While discussing the determinants of online collective action, patients pointed out what formed the DNA of these online communities they gather on and what were their founding characteristics and assets.

Recurrent values emerged from testimonies, such as the strong feeling of belonging, as well as its speed, the patients' expertise about their disease and related issues, the positive impact of online exchanges on patients' well-being.

7.3.1.1 Belongingness Speed and Strength

The peculiarity of these communities' approach, with regard to patients, is probably the speed and strength of bonds it creates. The users, upon entering this virtual world, feel immediately surrounded and supported by peers:

“Like I say to my friends, overnight, I got 10 friends, and then one month later, I got 50 friends. Now we are 9000 patients connected...and I immediately found a community...” (Breast cancer community patient)

“I realized that I had my first breast cancer in 1992 and now, in 2001, I’m still connected to this site... You see how strong it is...” (Breast cancer community patient)

7.3.1.2 Enlightened Patients

Virtual communities offer patients the positive response to their need for information, so much so that with this wealth of knowledge they may become experts. Besides, one of the striking features of these enlightened patients is that they often know how to use understandable language for the newcomers:

“Sometimes, patients are real experts and I can hardly follow the discussion.”
(Doctor)

“Yes, because I find tips and ideas from other parents who have children with the same syndrome, especially when it is very rare... and parents are more expert than doctors.” (Rare Disease Community patient family member)

7.3.1.3 Role in Healing

What is the healing power of this general phenomenon? When patients are asked whether online exchanges have increased their chances of recovery, their responses are often enthusiastic and affirmative:

"These forums can help you heal. I'm sure of that ... And I'm someone quite realistic ... I am sure that when you have positive thoughts and laughter despite all the things that happen to you, it helps you." (Breast cancer community patient)

These benefits (See Table 15.1) have to be differentiated from drivers for online collective action as they are caused by patient collaboration. Besides, although well documented and discussed in the above literature review (Fredrickson 2004; Fredrickson 2000), one should remain - not to argue the obvious - cautious about the impact of online collaboration on healing.

Table 15.1 Categorization and Secondary Concepts - Benefits of Online Collective Action

Broad Nodes	Sub-Nodes	Illustration	Number of References
Benefits of Online Collective Action	Belongingness Speed and Strength	“Immediately, when you approach it, you are taken under the wing of the other patients. And me, I was especially pleased ... I'm not very good, I'm not someone who goes on Facebook and all that. So I like things easy, I'm a little disinterested in the technology...So my first reaction has been to say: oops, it works and it works very quickly... And the fact that they replied very quickly, it was also very nice and I immediately felt the support.”*	18
	Enlightened Patients	“Yes because like us, she has a disability, she has a rare disease. Practitioners frequently tell me that, sincerely, they do not know enough about this disease. And they also say that they do not have all the knowledge parents show themselves...”**	13
	Role in Healing	“I am convinced that sharing positive emotions helps heal ... Here, there is not a direct exchange ... I think it really helps with the healing.”*	12

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

7.3.2 Background Factors

Following the benefits found in patients' collaborative work, they expressed background factors that should be taken into account while using virtual spaces. Among them, addiction or automatic behavior driving to patients' online connection - see the aforementioned concept of habits – was the most cited of online collective action surrounding constructs. Female ability to freely speak about almost any health-related matter also appeared spontaneously in testimonies (See Table 15.2).

7.3.2.1 Habits

Indeed, virtual communities have a highly addictive effect and affect a population that is imprisoned in idleness and pain. Therefore, they are a little more at risk of breaking contact with the real world from which they are already estranged:

"In difficult times, I think I was in auto mode connection. The first thing I did in the morning, on waking, was to log on to the forum, and after I took my breakfast and I accompanied my children to school ... In the evening, I spent another 2 or 3 hours ... Yes, it was an automatic reflex." (Breast cancer community patient)

7.3.2.2 Females Disinhibition

Due to our field of inquiry, we were mainly faced with females' on line behavior and from a consensual perspective, they are much more likely to reveal their feelings and tell their own stories when online:

"Women have much less difficulty in expressing their emotions, especially when online." (Health 2.0 expert)

7.3.2.3 Information Control

When considering background factors, patients called for the development of a better environment for these patients' online communities. As a result, the needs to be addressed would be: i) information to be better controlled, ii) online clinical advice to be provided.

Even if self-moderation does occur thanks to the wisdom of crowds, control of the released information about patients' everyday life is often considered inadequate.

Patients often fear the presence of inaccurate information, which frequently caused anxiety, particularly among the silent crowd of the community.

"After, it's always the same problem, depending on who manages the sites. We really need to be very strict and sites have to be moderated." (Breast cancer community patient)

7.3.2.4 Online Clinical Advices Requirement

In the wake of the fear of being misinformed by wrong statements, patients are demanding a professional presence that would certify the information's veracity on these platforms.

"I was also looking for people who had authority, people who seemed to be certified, licensed, relevant and legitimate with all the scientific and medical background." (Breast cancer community patient)

All these background factors, open virtual space excluded as explained above, are summarized in table 15.2.

Table 15.2 Categorization and Secondary Concepts – Background Factors			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Background Factors	Habits	“There is a risk of addiction, yes indeed. There is a risk of addiction to the extent that it is true that I do not spend a day without connecting there.”*	29
	Females Disinhibition	“There are women really there talking about their womb, their breasts. There are plenty of breasts, there are many wombs. And also printed somewhere was that she found her femininity, you know? These are beautiful exchanges. This is because they are women, mainly.”**	26
	Information Control	“This self-moderates, although moderation is required on these sites, it is unthinkable to leave women without safeguards.”**	18
	Online Clinical Advice Requirement	“This is where there should be scientific profiles, from the medical sector to speak on the subject, to provide expertise, to take time to answer questions online.”**	12

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

7.4 Summary of Results

Among the participants, information needs and belongingness needs remain the main reasons to reach and collaborate in virtual communities. However, testimonies also showed the emergence of new factors, such as the need to give-help, the desire for positive emotions, and the wish for platform exclusivity.

Conversely, fear of negative emotions, privacy protection and inaccurate medical information are major hindrances for patients who would otherwise be willing to join virtual spaces.

Characteristics related to social behavior have also emerged from interviews, including psychosocial impacts resulting from membership of these communities. Benefits from this commitment are noticeable, namely enhancement of decision-making processes and choices and the role in healing.

The needs and the perceived breaches of these platforms have also been underlined, highlighting the need for moderation of irrelevant comments coupled with a professional medical presence.

Many outcomes are drawn by the interviews and among the most important is the one that allows us to design a model of online collective action (See Figure 4). But we also stressed managerial contributions that can practically inform industry stakeholders about the reality from the inside.

8 – DISCUSSION AND CONCLUSION

8 DISCUSSION AND CONCLUSION

This study's central purpose was to examine the underlying determinants of online collective action on patients' communities, given the specificities of a patients' community typology that was chosen for this purpose.

Based on the Field Theory of Lewin (1947), the Expectancy-Value Theory (EVT) (Eccles et al. 1983), the model of goal directed behavior (MGB) (Perugini and Bagozzi 2001) and Dholakia et al. (2004) online resulting study; together with insights and transitive knowledge accumulated from the field (Bhaskar 2010); we conceptualized a model to predict online collective action on patients' virtual communities (See Figure 4).

When engaging in a patients 2.0-related research topic, we knew that the study would require specific attention on the diseases to be addressed. The preliminary interviews with experts suggested which way we should focus. The feedback was consensual and chronic or rare diseases were indicated to be suitable for such investigation.

Although we decided to focus on French participants, research performed in the US confirmed this choice, with Internet users living with chronic disease being more likely than other Internet users to access health information online:

“Living with chronic disease is also associated, once someone is online, with a greater likelihood to access user-generated health content such as blog posts, hospital reviews, doctor reviews, and podcasts. These resources allow an internet user to dive deeply into a health topic, using the internet as a communications tool, not simply an information vending machine” (Pew Internet Research 2010).

Understandably, the condition of rare disease patient also amplifies this need to spread their network far and wide and online connection will provide some answers:

“In rare disease communities, each person is an expert in observing the effects of a disease or a treatment on their own or a loved one’s body or mind. In this way, rare-disease patients and caregivers who gather together online are an example of a “smart” group...They are diverse and decentralized, yet able to pool knowledge and summarize their observations” (Pew Internet Research 2010).

Although this research was conducted in both communities, one should recalled that, as shown in table 3, out of the 37 interviews, 8 were performed on a rare disease community patient family member, 21 on a breast cancer community patient.

8.1 Coming back to the research questions

8.1.1 Discussion on Research Question 1

Patients’ testimonies highlighted that their online interactions were highly related to the concepts of giving-help in online contexts, that were studied in the literature. Bergquist and Ljungberg's (2001) featured three dimensions of giving-help online: other-orientation, bonding value and generalized reciprocity (See Table 12).

As a result the emotional support, the other-orientation dimension of giving-help contextualised within patients’ virtual spaces, prevails. What may be striking is that this dimension of the driving forces of their action, i.e. the search for positive emotions, is actually their most frequent social behavior, according to interviews.

Moreover, the giving-help through practical advice given for coping with day-to-day health situations, as well as general information providing, are the two other ways this collective action is emphasized in patients' feedback. Therefore, in a similar way, the very reason why patients join online, as the most frequently quoted driving force of online collective action – namely information needs, is also the way patients interact with others.

However, one should notice that, as they may be joining online in a greater need for information than positive emotions, emotional support seems to be predominating in their actual social behavior.

8.1.2 Discussion on Research Question 2

8.1.2.1 Driving Forces of Patients' Online Activity and Emergent Categories

Once the research field was defined, our concern was to determine the individual and social determinants of patients joining web-based patients' virtual communities, i.e. what would be the driving or restraining forces for patients to collaborate online.

As the literature guided us through what was learned from studies performed on online communities and what were patients' online behaviors, we were however questioning the emergence of new categories to deliver ad hoc transitive knowledge.

The driving forces for online collective action were segmented into three dimensions: utilitarian, social and hedonic values in accordance with EVT. Among the ones that were the most frequently quoted, the need to give and to get information (information needs)

and the need to belong to the community of peers (belongingness needs) were unsurprisingly enunciated.

The need to give help was also often expressed where we were expecting the need to get help. This highlights the principles of the gift economy – further discussed in the section below - as the foundation and cement of online communities that apply for diverse populations, including patients in the typologies studied. This also underlines the emergence of this new category – questioned at the beginning of this research - as a driving force of online collective action that is critical to the comprehension of online patients' behavior and incentives to participate.

Another category, related to the social dimension of the motivation to collaborate, actually emerged, namely exclusive value. As a matter of fact, it was quite unexpected to identify that, on one hand, patients would be inclined to give online support to others and, on another hand, that “the others” would be carefully restricted to the same categories of patients in a selective way of providing this help.

Finally and among the driving forces that were expected from previous studies, the positive emotions' category was little quoted, contrary to our expectations, as were group norms. These somewhat mitigated results do not remove the relevant aspect of these latter variables, and they would, whenever possible, have to be confirmed in a quantitative analysis to provide more solid conclusions on these insights.

8.1.2.2 Driving Forces of Patients' Online Activity and Gift Concepts

In our field of inquiry, the gift concepts bring a major added value to previous studies, especially with the three dimensions commented in the literature: other-orientation, bonding value and reciprocity.

Patients grouped in large online communities and sharing very similar day-to-day issues, demonstrate behaviors that apply to gift economies and spirit sharing. The cost-benefit rationality doesn't guide their online collective action through other-orientation characteristics. The will to help-back, even years after a remission, is not rare and emphasizes the importance for them to contribute to the group. The gift culture, highlighted by Rheingold (1995), is significant for patients' communities, where the bonding between participants is often immediate and especially of relevance, as the disease stigmatizes them.

Consequently, the bonding value and moreover the need to bond (belongingness needs) profoundly shapes their social relationships. New patients reaching the communities are adopted rapidly and with the confidence that s/he, sharing the group illness, belongs to the community. The bond formed is solid and will last for years, and often stays strong after the patient's recovery.

The question of reciprocity imposes the group norms and its social value impelling social exchange among actors. The aspects of reciprocity give to the group its social value. Molm et al. (2007, p.200) define reciprocity by two dimensions: i) its instrumental or utilitarian value or human capital, ii) its symbolic and communicative value or social capital, where "the symbolic or communicative value is the value conveyed by the act of reciprocity itself, over and above the instrumental value of the benefit provided".

Therefore, beyond the benefits provided to others during the act of reciprocity, the action itself, with uncertainty of other's reciprocity, brings value to the group, guide its norms and driving forces for patients' online collective action, strengthen other

dimensions of motives for engagement such as belongingness needs and positives emotions and may lower the cost variable in dimensions such as trust or privacy protection.

8.1.2.3 Restraining Forces of Patients' Online Activity and Emergent Categories

Interviews confirmed that when it comes to cost value of online collective action, the dimensions that have to be considered entail the concept of trust.

Obviously, trust then relates to a specific field of inquiry and would involve different facets depending on the players and their environment.

For patients' communities, the occurrence of trust supported literature insights implying the importance of privacy concerns and fear of inaccurate medical information.

Trust, often linked to issues of the quality of information in virtual communities, is a missing factor in IT models that has to be included in patients' communities (Dwyer et al. 2007; Fogel and Nehmad 2009; Luhmann 1979). Indeed, trust is a concept that is relevant when it comes to investment in personal relationships in a virtual context including a reciprocal approach (Grabner-Kräuter 2010). Therefore, this variable needs to be implemented in the patient engagement model with respect to the dimensions revealed by the interviews, namely, inaccurate medical information and privacy issues.

But above all, a major restraining force of patients' online collective action is negative emotions, triggered by what can be stated on collaborative platforms. They constitute the main obstacle for joining these virtual spaces. This fear was quoted quite frequently and

often elaborated with concrete examples of what can generate sorrow or anxiety among other negative emotions.

Therefore, we cannot really argue the emergence of new categories when aggregating literature's constructs. But considering that these literature insights came from different fields and that our underlying frameworks (Field Theory, EVT, MGB) were non health-related, many aspects appeared to bring new values, inspired from the field and in compliance with the general and stringent scope of models.

As a result, models and conclusions taken singly failed to draw the complete picture we depicted in the above sections, but this study remedies such breach.

8.2 Contribution

This study makes four major contributions to research and practice.

Firstly, this research shows what determines online collective action on patients' virtual communities and enriches the literature models such as MGB or EVT and their derivatives forms applied to online environments.

A broader literature review and interview evidence unearthed new constructs that add to social value dimensions – giving-help and exclusive value –, to utilitarian value dimensions – overcoming isolation – and to cost value dimensions – inaccurate medical information. In this regard, from theories taken from the social psychology arena, as well as extensively listening to insights provided by the field, we could develop a model of online collective action for patients gathered in virtual communities (See Figure 4).

From guidance provided by interviews' feedback, we chose to focus on patient's virtual communities rather than patient's social networks. Indeed, as virtual communities imply strong ties between individuals, bonding value and emotional support, and as the sense of belongingness is a key determinant of online collective action, these community virtual spaces for patients were indicated to be relevant for our study.

Secondly, we researched beyond IS adoption, which fails to depict users as social actors and to frame interdependencies-in-use. We contextualized IT use in the e-health domain, and contributed to the analysis of online collective action of patients, enabling the drawing of a model using literature and field knowledge.

Using a critical realism design helped us get insights from the field along with a literature review exploring different arenas and combining complete theories well suited for patients' online usage (Field Theory, EVT, MGB and the gift concepts). This helped to understand why patients are motivated to act online and interact with other patients through technology, but driven by determinants other than the IT tools themselves.

As a result, system usage and IT artifacts have to be learned but do not contribute a response to the research questions. For that purpose, knowledge of social psychology is also needed in order to draw the right field forces of online collective action, especially with a population of patients.

Thirdly, we were able to reveal contextual designations behind patients' online collective action. Indeed, from the literature we already discovered that the functioning of virtual

communities relies on gifts as a way of: i) helping others and their well-being (other-orientation), ii) developing strong ties (bonding value), iii) creating mutual satisfaction which doesn't depend on who gives or who gets as long as exchanges endure (generalized reciprocity).

So, the present research offers the contextual designations for these three dimensions in the context of patients' communities. Values emerged from the field in compliance with literature underlying framework and are as follows: i) emotional support activity (other-orientation), ii) sharing information about practical advice (bonding value), iii) giving general information and social exchange activity (generalized reciprocity).

Furthermore, on one hand, one can notice the correspondence between the hedonic driving force for online collective action – positive emotions – and the emotional support activity that does actually result from patients' activity. On the other hand, there is also a correspondence between the utilitarian driving force for online collective action – information needs – and the sharing of information, whether health-related or from a general perspective, that can be found on patient's virtual spaces.

Finally, we could highlight the trust aspects that are relevant in patients' virtual worlds. The study shows that the need for patients to contribute to the others' well-being is rooted in their behavior and of the utmost importance. It also shows that inaccurate medical information and privacy concerns decrease interaction with peers through the online communities.

In demonstrating this, the study applies a rigorous exploratory approach that makes the results more compelling and relevant because they specifically take into account the context of patients' use of health-related virtual communities. These results should help Health 2.0 practitioners to better address these issues and interpret the factors they can leverage in order to encourage experience sharing among patients.

In this regard, insightful comments were received, such as the need for information control, the need for online clinical advice that would be performed by health professionals and the wish to leave virtual spaces open. The first two would imply a more involved medical presence in patients' platforms, which is already the case in many examples, but not always systematic. The last point would need confirmation and has been dropped by our interpretive research approach, due to the very few references to this matter as well as to weak or unfounded claims from patients' perspectives, and understandable ethical issues. Furthermore, it goes against the common practice. Indeed, patients' platforms often require users to log in to be allowed to read forum contents.

To conclude, a major concern should be highlighted behind these trust issues, with a growing and ageing worldwide population, and growing Internet use. In the particular case of patients often experiencing the burden of loneliness when faced with illness, these issues, designed in this research by the possible lack of medical accuracy of information or privacy protection can demotivate them and dampen their strength or capability to recover in the best possible conditions.

8.3 Limitations and Future Research

We conducted a high number of interviews, due to our volition to operate preliminary ones in order to get to know what patients would be more concerned with by our research, and in order to reach semantic saturation. Despite this fact, we consider this qualitative research as an intermediate exploratory phase that would require a quantitative phase in order to be able to draw further conclusions as well as a complete model of patients' online collective action (Laubie and Elie-Dit-Cosaque 2012).

From its inception, this thesis has been designed to be the first part of an ongoing research process, whose aim is to further validate the insights brought by both the literature exploration and the interviews.

Indeed, this research presents limitations and therefore opportunities for further investigations.

Firstly, we targeted French patients in order to avoid introducing biases from multicultural settings. Therefore, future research may explore differentiations and/or similarities of behavior of patient's online collective action.

Secondly, preliminary interviews suggested focusing on specific patients' virtual communities. It may also be relevant to investigate populations other than the breast cancer community and a community of parents of autistic children, whether mixed or exclusive types of patients gathered on the same platform. It may also be advisable to explore the attributes of social networks in order to compare the results to those of virtual communities when it comes to patients as users.

Thirdly, our patients interviewed were mostly female. Extending this study to both genders or exclusively to male patients may drive interest for comparing results.

Finally, all concepts that were considered secondary would have to be carefully taken into account in order to make conclusions on their relevance, i.e.: the influence of IT artifacts and background factors.

Indeed, we account for the role of a number of background factors in the model that would require investigation in a possible follow-up quantitative study. Ajzen 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).

Ajzen 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 have to be 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, media exposure and habits. 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.

Future research may hence try to identify variations across these background factors regarding the determinants of online collective action on patient's online communities.

8.4 Conclusion

The gift concepts, EVT, MGB, following Lewin's underlying framework, applied to virtual communities, offer important information concerning the leading determinants of online collective actions for patients. However some adjustments have to be made to fit our field of enquiry in patients' virtual communities. Indeed, our community-based background of patient members includes a large number of users, most often weakened by their disease, seeking interaction on these platforms.

Although the emotional dimension remained meaningful in patients' motives for joining online communities, the findings suggest that the MGB failed to offer a relevant model for predicting intentional action to engage online. The gift concepts complete the lack of an explanation, highlighting the notion of help-giving and the social value that are comprised of determinants such as belongingness needs or exclusive value.

Furthermore, the interviews demonstrate that the model was still lacking variables concerning the cost that explains patients' reluctance to join these communities. Indeed, the concept of trust embodied by the relevant medical information has to be considered as a predictive variable together with the concept of security of use embodied by a

privacy protection concept. Other utilitarian values, such as information, needs to be integrated in the model, as they are in the adaption of MGB in Dholakia et al. (2004) past study.

These above mentioned aspects contribute to expand this trend of developing virtual spaces for people seeking information and support online. The Internet and patients' initiatives are changing the face of medical practice, previously limited to a top-down approach where health professionals and third parties involved communicated a restricted amount of information to patients.

We hope that by connecting to virtual communities patients will have an improved quality of life, due to the benefits provided, which are often different from those they would get from traditional social groups operating in real life. We hope that researchers and stakeholders will contribute to this problem-solving, as this research has helped to better take into account the ageing population's health challenges and emphasized how patient's virtual communities can help support patient's concerns.

9 - ANNEXES

9 ANNEXES

9.1 Annex 1: Propositions

Proposition 1: Giving-Help is positively related to online action regarding virtual patients' communities.	97
Proposition 2: Belongingness Needs is positively related to online action regarding virtual patients' communities.....	98
Proposition 3: Group Norms is positively related to online action regarding virtual patients' communities.	99
Proposition 4: Exclusive Value is positively related to online action regarding virtual patients' communities.	100
Proposition 5: Information Needs is positively related to online action regarding virtual patients' communities.	101
Proposition 6: Instrumental Needs is positively related to online action regarding virtual patients' communities.	101
Proposition 7: Overcoming Isolation is positively related to online action regarding virtual patients' communities.....	102
Proposition 8: Positive Emotions is positively related to online action regarding virtual patients' communities.	105
Proposition 9: Navigational Structure is positively related to online action regarding virtual patients' communities.....	108
Proposition 10: Visual Appeal is positively related to online action regarding virtual patients' communities.	108

Proposition 11: Negative Emotions are negatively related to online action regarding virtual patients' communities..... 112

Proposition 12: Privacy Protection is negatively related to online action regarding virtual patients' communities. 113

Proposition 13: Inaccurate Medical Information is negatively related to online action regarding virtual patients' communities. 113

9.2 Annex 2: Dictionaries of a Priori Themes#1

Table 16.1 Open Codes for Driving Forces of Online Collective Action		
Broad Nodes	Sub-Nodes	
Driving Forces for Online Collective Action	UV*	Information Needs
	SV**	Belongingness Needs (Social Identity)
	SV**	Giving Help
	HV***	Positive Emotions
	SV**	Group Norms
	UV*	Instrumental Needs
	UV*	Navigational Structure
	HV***	Visual Appeal

*Utilitarian Value **Social Value ***Hedonic Value

Table 16.2 Open Codes for Restraining Forces of Online Collective Action	
Broad Nodes	Sub-Nodes
Restraining Forces for Online Collective Action	Negative Emotions
	Privacy Protection

Table 17 Open Codes for Online Collective Action	
Broad Nodes	Sub-Nodes
Generic Designation	Giving-Help (Other-Orientation)
	Giving-Help (Bonding Value)
	Giving-Help (Generalized Reciprocity)

Table 18 Open Codes for Background Factors of Online Collective Action	
Broad Nodes	Sub-Nodes
Background Factors	Habits

Table 19 Open Codes for Benefits of Online Collective Action	
Broad Nodes	Sub-Nodes
Benefits of Online Collective Action	

9.3 Annex 3: Dictionaries of Themes#2

Table 20.1 Open Codes for Driving Forces of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number references
Driving Forces for Online Collective Action	UV*	Information Needs “I had a question”, “asked a question”, “I got the answer”, “girls explain”, “share information”, “looking for information in order to know”	101
	SV**	Belongingness Needs (Social Identity) “bound by the same diseases”, “share the same experience as us”, “I feel like this is my family”, “this relational we share”, “I needed to talk to women sharing the same disease”	94
	SV**	Giving Help “to help others”, “to cheer them up”, “supporting relationship”, “as long as it can help others”, and even when it can make a difference, “give them tips”	67
	SV**	Exclusive Value “sharp people in the field, in the pathology and it is very reassuring”, “we know that this person is concerned”	61
	HV***	Positive Emotions “positive emotions”, “successful experience”, “an operation that succeeded”, “when you feel that parents are pleased”, “people's emotions”	61
	UV*	Overcoming Isolation “the disease is a social handicap”, “I am a bit lonely”, “come out of my isolation”,	44
	SV**	Group Norms “we share the same vision”, “same thoughts”, “people who share my problems, my opinions, my values”	31
	UV*	Instrumental Needs “when girls explain”, “I can find no answer” “they give you the information you need’,” “give tips”	30
	UV*	Navigational Structure “website is fluid”, “it meets my needs”, “user-friendly interface”	26
	HV***	Visual Appeal “the appearance of the website”, “website page is catchy”	12
	UV*	Preference over Medical Process “more easily than taking an appointment with a doctor”, “administrative medical system”	5
	HV***	Doctors Positive Perception “my doctor recommended me the website”, “my doctor indicated me the community”	4
HV***	Boredom Avoidance “need to do something”, “I have more time”	3	

*Utilitarian Value **Social Value ***Hedonic Value Codes Added From the Field

Table 20.2 Open Codes for Restraining Forces of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of references
Restraining Forces for Online Collective Action	Negative Emotions	“negative diagnosis”, “punch in your stomach”, “your fear is coming back and spreading”, “negative emotions”, “anxiety”, “more afraid”, “announce their bad news”, “diagnosis of metastases”	46
	Privacy Protection	“it exposes you”, “confidential information”, “control”, “confidentiality of data”, “the Internet is risky”, “sense of security”	33
	Inaccurate Medical Information	“they aren’t necessarily enlightened patients”, “not been validated”, “invalidated information”, “can be dangerous”	30
	Complexity of Information	“difficult to understand”	2

Codes Added From the Field

Table 21. Open Codes for Online Collective Action

Broad Nodes Generic Designation	Broad Nodes Contextual Designation	Key Terms and Phrases	Number of References
Giving-Help (Other-Orientation)	Emotional Support	“so much support”, “seeking consolation”, “feelings”, “state of fragility”, “find keen listeners”, “I gave consolation”, “you become the one who helps”	49
Giving-Help (Bonding Value)	About practical advices for coping with day-to-day health situations	“being in a community of patients sharing the same disease”, “share”, “help to better live it”, “good advices”, “communicate on specific information”	35
Giving-Help (Generalized Reciprocity)	About General Information (Medical or Miscellaneous)	“We asked each other’s about health topics”, “general information”, “we talk about everything”, “any kind of information”	31

Codes Contextual Designation Added From the Field

Table 22. Open Codes for Background Factors of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Background Factors	Habits	“risk of addiction”, “I do not spend a day without connecting”, “automatic”, “automatic behavior”, “I don’t realize I got connected”, “every day”	29
	Females Disinhibition	“There are women really them talking about their womb”, “women express their emotions more easily”, “women may reveal more of themselves”	26
	Information Control	“This self-moderates”, “moderation is required”, “safeguards.”	18
	Online Clinical Advices Requirement	“there should scientific profiles”, “from medical sector to speak on the subject”, “to provide expertise”	12
	Open Virtual Space	“it to be open”, “open is normal”	7

Codes Added From the Field

Table 23. Open Codes for Benefits of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Benefits of Online Collective Action	Belongingness Speed and Strength	“Immediately”, “taken under the wing of the other patients”, “I immediately felt the supported”	18
	Enlightened Patients	“sometimes, patients are true experts”, “they are more experts than doctors”	13
	Role in Healing	“I am convinced that sharing positive emotions helps heal”, “we feel better, more quickly”	12

Codes Added From the Field

9.4 Annex 4: Dictionaries of Themes#3

Table 24.1 Open Codes for Driving Forces of Online Collective Action			
Broad Nodes	Sub-Nodes	Key Terms and Phrases	References
Driving Forces for Online Collective Action	UV*	Information Needs “I had a question”, “asked a question”, “I got the answer”, “girls explain”, “share information”, “looking for information in order to know”	101
	SV**	Belongingness Needs (Social Identity) “bound by the same diseases”, “share the same experience as us”, “I feel like this is my family”, “this relational we share”	94
	SV**	Giving Help “to help others”, “to cheer them up”, “supporting relationship”, “as long as it can help others”	67
	SV**	Exclusive Value “sharp people in the field, in the pathology and it is very reassuring”, “we know that this person is concerned”	61
	HV***	Positive Emotions “positive emotions”, “successful experience”, “an operation that succeeded”, “when you feel that parents are pleased”, “people's emotions”	61
	UV*	Overcoming Isolation “the disease is a social handicap”, “I am a bit lonely”, “come out of my isolation”	44
	SV**	Group Norms “we share the same vision”, “same thoughts”, “people who share my problems, my opinions”	31
	UV*	Instrumental Needs “when girls explain”, “I can find no answer” “they give you the information you need”, “solve practical problem”, “give tips”	30
	UV*	Navigational Structure “website is fluid”, “it meets my needs”, “user-friendly interface”	26
	HV***	Visual Appeal “the appearance of the website”, “website page is catchy”	12
	UV*	Preference over Medical Process “more easily than taking an appointment with a doctor”, “administrative medical system”	5
	HV***	Doctors Positive Perception “my doctor recommended me the website”, “my doctor indicated me the community”	4
HV***	Boredom Avoidance “need to do something”, “I have more time”	3	

*Utilitarian Value **Social Value ***Hedonic Value

Codes Added From the Field Codes Dropped by the Researcher Interpretive approach

Table 24.2 Open Codes for Restraining Forces of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of references
Restraining Forces for Online Collective Action	Negative Emotions	“negative diagnosis”, “punch in your stomach”, “your fear is coming back and spreading”, “negative emotions”, “anxiety”, “more afraid”, “announce their bad news”, “diagnosis of metastases”	46
	Privacy Protection	“it exposes you”, “confidential information”, “control”, “confidentiality of data”, “the Internet is risky”, “sense of security”	33
	Inaccurate Medical Information	“they aren’t necessarily enlightened patients”, “not been validated”, “invalidated information”, “can be dangerous”	30
	Complexity of Information	“difficult to understand”	2

Codes Added From the Field

Codes Dropped by the Researcher Interpretive approach

Table 25. Open Codes for Online Collective Action

Broad Nodes Generic Designation	Broad Nodes Contextual Designation	Key Terms and Phrases	Number of References
Giving-Help (Other-Orientation)	Emotional Support	“so much support”, “seeking consolation”, “feelings”, “state of fragility”, “find keen listeners”, “I gave consolation”, “you become the one who helps”	49
Giving-Help (Bonding Value)	About practical advices for coping with day-to-day health situations	“being in a community of patients sharing the same disease”, “share”, “help to better live it”, “good advices”, “communicate on specific information”	35
Giving-Help (Generalized Reciprocity)	About General Information (Medical or Miscellaneous)	“We asked each other’s about health topics”, “general information”, “we talk about everything”, “any kind of information”	31

Codes Contextual Designation Added From the Field

Codes Dropped by the Researcher Interpretive approach

Table 26. Open Codes for Background Factors of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Background Factors	Habits	“risk of addiction”, “I do not spend a day without connecting”, “automatic”, “automatic behavior”, “I don’t realize I got connected”, “every day”	29
	Females Disinhibition	“There are women really them talking about their womb”, “women express their emotions more easily”, “women may reveal more of themselves”	26
	Information Control	“This self-moderates”, “moderation is required”, “safeguards.”	18
	Online Clinical Advices Requirement	“there should scientific profiles”, “from medical sector to speak on the subject”, “to provide expertise”	12
	Open Virtual Space	“it to be open”, “open is normal”	7

Codes Added From the Field

Codes Dropped by the Researcher Interpretive approach

Table 27. Open Codes for Benefits of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Benefits of Online Collective Action	Belongingness Speed and Strength	“Immediately”, “taken under the wing of the other patients”, “I immediately felt the supported”	18
	Enlightened Patients	“sometimes, patients are true experts”, “they are more experts than doctors”	13
	Role in Healing	“I am convinced that sharing positive emotions helps heal”, “we feel better, more quickly”	12

Codes Added From the Field

Codes Dropped by the Researcher Interpretive approach

9.5 Annexe 5: Researcher Profile

9.5.1 Teaching Experience, Corporate Experience and Education

I am fortunate to work in the health sector since 2006. At that time, a choice was proposed and it has promptly become self-evident that I wished to work in the health sector and specifically in an online environment.

Early, before the creation of Facebook and Twitter, my business partners, themselves health professionals and " 2.0" visionaries, created a virtual community where health professionals could discuss their daily practice. Working with them gave me early on extensive knowledge about virtual communities' day-to-day functioning and an interpretive willingness to conduct research in this field.

Besides these activities, I always valued teaching experiences and was lucky to be given these opportunities by prestigious institutions.

My whole corporate experience and education are summarized in tables 28, 29, 30.

Table 28. Researcher Profile – Teaching Experience

Institutions	Period	Position Held	Expertise
Dauphine University	Since 2012	Corporate Lecturer	Web 2.0, Open Innovation, Social Media
EM Lyon	Since 2011	Corporate Lecturer	Web 2.0, Open Innovation, Social Media
ESCP Europe	Since 2011	Affiliate Professor	Web 2.0, Open Innovation, Social Media, Health 2.0
	2009 - 2011	Corporate Lecturer	Web 2.0, Open Innovation, Social Media
HEC Geneva	2009	Corporate Lecturer	Organizational Behavior & Coaching

Table 29. Researcher Profile - Corporate Experience			
Organizations	Period	Position Held	Achievements
HEXAP <i>Registry, applicant for .med, Domain Name Industry</i>	Since 2012	Co-Founder, President	- Fundraising - Brand and online policy creation - Sales & Services development
ABCDENT <i>Media, e-Business and Social Network, HealthCare Industry</i>	Since 2008	Partner, Strategy & Operations Manager	- Strategic and worldwide operational development - New brands creation - Sales & Services development
PROMOPIXEL <i>Web Agency & Registry</i>	Since 2008	Partner, Strategy & Operations Manager	- Strategic and worldwide operational development - New brands creation - Sales & Services development
AB SURGERY <i>Consulting Agency, HealthCare Industry</i>	Since 2006	Founder & Executive Manager	- First Entrepreneurial Experience - Sales & Services development - Health ongoing training accreditation integration
ZODIAC AEROSPACE (ACC LA JONCHERE) <i>Aerospace Equipments Manufacturer</i>	2003 – 2007	Group Purchase Manager	Strategic and operational development of processes rationalization (Lean, Supply chain...)
		Executive Director of Security Group's Division	- Board Member - Development and implementation of a new B.U in medical and dental field, for block surgery security
		International Sales Manager of Security Group's Division	- Rationalization of the distributor network - Development of sales in video increase of 25% over 3 years
SWISS LIFE (Wargny) <i>Bank</i>	1998 – 2002	Financial Markets Operator / Financial Analyst / Financial Consultant	
SEPTEC <i>Consulting Agency</i>	1996 – 1998	Junior Consultant CCTV Solutions & Luxury Products North America	

Table 30. Researcher Profile - Education	
Institutions	Degree
ESCP Europe	Executive MBA
Paris VIII	MSc. Organizational Behavior
UFR Sciences Nantes	MSc. Physics

9.5.2 Presentations and Publications in Conferences with Peers Reviews

Convinced that the exchange within the academic world and that peers reviews would greatly be beneficial for my work, I very early on wished to present my work in progress in conferences. I had already participated in some of them as an entrepreneur and in the field of Health 2.0 and it is not uncommon in health industry meetings to mix genres between startups and academic research. I had the chance to present my work in five conferences, including three oral presentations (ICEMS2011, MedX2012 and ICIS2012) (See Table 31).

Table 31. Researcher Profile – Presentations and Publications in Conferences with Peers Reviews

Institutions Conferences - Journal	Period Reference	Authors	Title
Association Information et Management	December 15, 2013	Laubie, R., Elie-Dit- Cosaque, C.	System Usage and Social Behaviors in Web 2.0 Environments: Conceptualizing and Predicting Online Collective Action. Research Paper
International Conference on Information Systems	December 16-19, 2012	Laubie, R., Elie-Dit- Cosaque, C.	Exploring and Predicting Online Collective Action on Patients' Virtual Communities: a Multi-method Investigation in France. Research Paper
Stanford University MedX	September 28-30, 2012	Laubie, R.	Examining the Impact of Hedonic Value and Trust on Patients' Communities Online Action: an Extended Model of Social Networks Goal- Directed Behavior. Research Paper
Harvard University Medicine 2.0	September 15-16, 2012	Laubie, R.	Expectancy-Value Model of Patients' Virtual communities. The Determinants of Desires for Online Collective Action. Research Paper
Stanford University Medicine 2.0	September 16-18, 2011	Laubie, R.	Understanding the Determinants of Online Collective Action. The Case Study of Patients Communities. Research Paper
Case Western Reserve University International Conference on Engaged Management Scholarship	June 2-5, 2011	Laubie, R.	Extended Model of Social Networks Goal- Directed Behavior. The Role of Anticipated Amotions and Habits. Research Paper
Expansion Management Review	2011, n°143, pp.24-31	Laubie, R.	Le Patient Connecté ou les Métamorphoses de la Santé

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