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ONLINE PATIENTS KNOWLEDGE SHARING: THE ROLE OF WEB PEER EXCHANGES IN THE DIABETES CARE

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Introduction

"....si...è stato davvero bello!!!! ma...altro che 2 chiacchiere....fiumi e fiumi di parole in pochi, troppo pochi minutiiii!!!!! ;) <3 E il grazie + grande di tutto ciò va...a questo gruppo!!!" [...it was really beautiful!!! More than a little chat... blue streak in few, very few minutes!!!! ;) <3 (little hearth) The biggest thanks for this ...to this group!!!] (excerpt from a Facebook group for diabetes patients and caregivers)

Joy, enthusiasm and thankfulness toward a group of people, who share the same experience of illness, that has become really important in the life of this person...

Trying to detach ourselves from the emotions expressed in these words, we can assert that the Internet, and in particular Web 2.0 has totally changed the health promotion and the patients' education panorama. Literature has established that patients (in particular, chronic patients) and their caregivers use the Internet and especially online peer exchanges to find more information about their condition and to seek support from other patients.

Although the importance of these online peer exchanges in health, literature focused more on the outcomes of the exchanges (namely contents and knowledge produced in the exchanges) and less on:

- The ways in which these contents are constructed.
- The role of online context into shape the processes.

This dissertation will propose a research aimed to study the online knowledge sharing and construction processes between patients, by focusing on the specific case of diabetes in Italy.

The work is a qualitative research, informed by ethnography, composed by three main studies (steps), strictly connected and consecutive. Briefly:

- Study 1 is aimed to map the online contexts (considering both their social and technical features) in which online peer exchanges about diabetes happen in order to understand: 1. if and how different online contexts may shape different knowledge processes and 2. what are the online contexts able to support knowledge sharing and construction processes. It is based on a systematic exploration of Web 2.0.
- Study 2 is aimed to understand what social and contextual conditions of the online contexts can support or hinder knowledge sharing and construction processes. It is based on a monitor of the online contexts able to support knowledge sharing and construction detected by study 1.
- Study 3 is aimed to understand how the online knowledge sharing and construction processes work. We analyzed interactions happening in the online contexts, detected by study 1 and 2, by constructing and ad hoc grid who considered: temporal development of the process (main steps), interactive (discursive and conversational) strategies, and contents.

The presentation of this research work is articled in the following chapters:

- ✓ Chapter 1 gives an overview of the online peer exchanges about health, framing their role in the patient empowerment perspective and by identifying the state of the art and the challenges in the study of these exchanges.
- ✓ Chapter 2 globally presents the research project by defining: the research case, the research purposes, the research plan and the methodological approach.
- ✓ Chapter 3 presents Study 1: theoretical background, main aims, method, main results, discussion and conclusion.

- ✓ Chapter 4 presents Study 2: theoretical background, main aims, method, main results, discussion and conclusion.
- ✓ Chapter 5 presents Study 3: theoretical background, main aims, method, main results, discussion and conclusion.
- ✓ Conclusion: final general reflections on the main findings and on the relevance of the research work are discussed.

CHAPTER 1

Chronic Illness, web, peer exchanges and knowledge sharing and construction processes: what challenges?

Questo gruppo è dedicato a tutte le mamme che hanno un bambino diabetico e che si trovano quotidianamente ad affrontare tanti problemi, dovuti alle difficolta' che questa condizione porta. Confrontarsi, Supportarsi Aiutarsi e Informarsi, questi sono gli obiettivi che questo gruppo propone, senza mai volersi sostiurire al consiglio dell'esperto [This group is dedicated to all moms of a diabetic child; they have to daily face many problems connected to their children condition. The aims of this group are:

Confronting, Supporting, Helping, Inform, without take the place of the expert.]

(excerpt from a Facebook group for diabetes caregivers, see Chapter 5)

What happens when people stumble on an online group/forum/social network in order to find help for an health issue (in particular connected to a chronic condition)? Why do people decide to use this kind of tools?

Starting from some real evidences, this chapter will be a trip across health and web, acted to define how chronic diseases (such as the mentioned above diabetes) can be approached in order to better manage them, by clarifying the possibility that technologies can give to the chronic diseases care, focusing on the role of Internet and

in particular of peer exchanges in the management of chronic conditions, defining what is the state of the art, what the gaps and what the challenges.

1.1 Constructing a patient paradigm

In the world, the 63% of deaths in 2008 were "due to NCDs (noncommunicable diseases"), principally cardiovascular diseases, diabetes, cancer and chronic respiratory diseases" (World Health Organization, 2011, p. vii).

"In Italy, people that have a chronic illness are 38,4% of the entire population" (ISTAT, 2012).

The incidence of chronic diseases and in particular of NCDs is evident and the necessity of a global intervention is clear. Intervention means prevention; as a matter of fact, most NCDs are strongly associated and causally linked with four particular behaviours: tobacco use, physical inactivity, unhealthy diet and the harmful use of alcohol (World Health Organization, 2011). Intervention means therapies and medicines. But intervention means more and more daily management of several aspects of life, such as diet, physical activity, but also stress or time management; in fact, various NCDs (such as diabetes or hypertension or respiratory diseases) are well balanced by an healthy lifestyle that often is the key factor to avoid the consequences (that, in some cases, can converge on the death of the patient).

Starting from this scenario, the management of chronic diseases and in particular the active role of the patient and his/her caregivers (using the term "caregiver" we refer to the people that help patient the in his/her daily care, such as parents or children) represents one of the public health system's priority. In particular it's necessary to understand how to **promote "good practices" in the daily life** (Carrà Mittini, 2008).

According to this idea, we propose two concepts that are really reconfiguring the health paradigm.

They lay on two strictly linked approaches to care&cure.

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¹ It "is a disease which is not contagious. Such diseases usually derive from genetic predisposition and/or certain lifestyle characteristics. [...] For example, NCDs [noncommunicable diseases] are obesity, diabetes, hypertension" (Kirch, 2008, p. 993).

The first concept concerns with the way to consider the patients: the "patient centeredness", namely "treating the patient as a unique individual. It is a standard of practice that demonstrates a respect for the patient, as a person [...]. It is very much about considering the patient's point of view and circumstances in the decision-making process" (Pelzang, 2010, p. 912). As health practitioners, we have to consider the patient as holder of a whole subjective experience related to health and illness (Braibanti, Strappa, & Zunino; 2009) that is necessary to succeed in treatment (Holmstrom, & Roing, 2010).

Practically, the real and shared aim of this paradigm is promoting health in the everyday life.

At this point it's possible to link the second concept: the patient empowerment; it concerns with the way to help and sustain patients and their care. It's an approach that allow patient to learn how to manage and eventually change their health lifestyles. In particular, patient empowerment is "a process when the purpose of an educational intervention is to increase one's ability to think critically and act autonomously. Empowerment is an outcome when an enhanced sense of self-efficacy occurs as a result of the process" (Anderson, & Funnell, 2010, p. 278). The assumption is that "to be healthy, people must be able to bring about changes, not only in their personal behaviour, but also in their social situations and the organizations that influence their lives" (Feste, & Anderson, 1995, p. 140). The Patient empowerment paradigm is mainly used in the management of chronic diseases (Anderson, & Funnell, 2010).

Practically both concepts are focused on (Holmstrom, & Roing, 2010):

- Improving the communication process between health practitioners and patients.
- Rejecting the "sick role" of patients.
- Educating patients to be more active in their care and cure.
- Considering all the activities in the life of the patients (such as support groups or the Internet) as a way of empowering.

Moreover, the patient empowerment perspective focuses more on the increasing of patient's knowledge and personal development (Anderson, & Funnell, 2010) and the outcome of the process is to make the patient the main decision maker and the responsible one for all his/her care.

We think that this is the most useful perspective in the management of chronic illness as daily care management is really difficult and it requires continuous decision processes.

Even if the Italian medical situation uses to be really far from this model and it considers the doctor the only decision maker in the care, also in the case of chronic conditions (Musacchio *et al.*, 2010), it's essential to promote these ideas and to identify where interventions are possible.

So, this perspective will be the framework and the guide of our research work.

1.2 The use of ICT technologies in the Patient Empowerment perspective: the e-health

"The World Health Assembly resolution recognized the potential of eHealth to strengthen health systems and to improve quality, safety and access to care, and encouraged Member States to take action to incorporate eHealth in health systems and services" (World Health Organization, 2012).

More and more the use of ICT (and all new technologies) is becoming central for the management of health and chronic diseases. In fact it allows to reduce the care management costs and it has been used successfully in the chronic disease management (Wise *et al.*, 2007).

All the activities related to the use of information and communication technology (ICT), and in particular the use of the Internet, in the health care labelled as e-health.

In 2001, Eysenbach defined e-health as

an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology (paragraph: Introduction).

More recent papers define e-health as (Keogh, Rosser, & Eccleston, 2010): "electronic communication-based technologies to aid or provide healthcare in some form" (p. 18) and e-health tools and activities as "designed to improve health surveillance, health-

system management, health education and clinical decision-making, and to support behavioural changes related to public-health priorities and disease management" (Piette et al, 2012, p. 365).

Each definition shows the broadness of this concept.

For the sake of simplicity, we can just say that e-health comprehends all the activities related to the use of information and communication technology (ICT) in the health care. The term refers mainly to Internet based activities, but it comprehends other technologies, such as computer assisted care management program (Jiang, Huang, Yan, Cui, Tang, & Xiang, 2010) or virtual reality (Gorini, Gaggioli, Vigna, & Riva, 2008). It's easy to imagine the variety of interventions can be developed in this area.

Trying to schematize, the e-health framework comprehends:

- Clinical and administrative information systems (Carrasqueiro, & Monteiro, 2010).
- Transactions functions, such as refilling medications, requesting an appointment, or release of information (Ahern, Woods, Lightowler, Finley, & Houston, 2011).
- Supporting the daily cure and care, such as remote monitoring, telecare and telemedicine (Lee, Helal, Anton, De Deugd, & Smith, 2012).
- Prevention programs (Shaw *et al.*, 2006).
- Health worker (practitioners, nurses...)- patient relation facilitators (Perez, 2009) and clinical relation support (Graffeo, & La Barbera, 2009).
- Continuous medical education/ e-learning (Curran, Murphy, Abidi, Sinclair, & McGrath, 2009).
- Information search (using: search engines, websites, forums...) (Ayers, & Jacobs Kronenfeld, 2007).
- Peer-to-peer exchanges (Ancker, Carpenter, Greene, Kukafka, Marlow, & Prigerson,,
 2009).

According to Oh *et al.* (2005) review about e-health interventions, e-health is everything connected both to health and technology.

In our perspective, the connection between all the e-health activities (and their value) is the logic under their construction. In fact, according to Eysenbach (2001), the "E" in ehealth doesn't mean just electronic but it refers to a world of values that characterizes all the interventions and activities as Efficient and high quality, oriented to improve patients and health professionals Experience and their relationship, careful about Ethics, guarantor of Equity in the exchange and scientific rigor.

Considering the activities designed for patients, the main goal is their empowerment throughout interventions and tools that make them more and more able to manage their care.

1.3 Internet for health purposes

A research edited by ISTAT² (2011) reports that the 45,1 % of the Italian Internet users (that are the 54,5 % of the Italian population) use the Internet to find health information. This means that around the 25% of the Italian people use the Internet for health reasons. Moreover, this is the result of a growing trend (from 40, 1 % Internet users in 2010 to 45,1% in 2011 search health information on the Internet) and the Internet is less connected to high socio-cultural groups, but it's more and more becoming a mass phenomenon.

Today, seeking and providing health information is one of the main reasons to use Internet. This area of e-health has great potentialities as the patients (but also health professionals and researchers) themselves "go" to the Internet.

The use of Internet for health purposes is called "consumer health informatics", namely "the study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumers" (Ferguson, 2001, p. 2). People that suffer from chronic conditions use the Internet significantly more than healthy people (Siliquini *et al.*, 2011).

As we already said, these activities can be really interesting for patients' empowerment potentials.

In particular, we believe that the Internet is changing the health paradigm in three main ways:

• Searching health information: by using the Internet, it's possible to find every kind of information. The patient is more and more the main character in the decisions regarding his/her health because he/she can have a lot information from many different sources of information. Consequently, patients are becoming increasingly

² Italian statistical research institute.

independent in the process of information-seeking and decision-making about self-care (de Boer, Versteegen, & Wijhe, 2007). Researcher and health professionals are making a huge effort in order to improve the use of Internet searching by patients (or lay people) in a twofold way: understanding who use Internet for health reasons (Ayers, & Kronenfeld, 2007), what are the motives to reach information from internet (MacMullan, 2006) and how people look to Internet for information (Schaffer, Kuczynski, & Skinner, 2008); trying to construct websites regarding health topics more usable (Goldberg *et al.*, 2011) and containing helpful and truthful (Irwin, Thyvalikakath, Spallek, Wali, Kerr, & Schleyer, 2011) information.

- Relationship between health professionals and patients: Internet facilitates patient provider relationship and the related services (e.g.: online consulting service) (Kraus, Stricker, & Speyers, 2011). But the Internet doesn't change just technical and practical aspects of this relations; as we said, the patient has more information and a lot of information sources; for these reasons, the relationship between practitioner and patient is less asymmetric (Wald, Dube, & Anthony, 2007) and the setting rules of this relationship are changed (eg: moments and ways to communicate) (Guseh, Brendel, & Brendel, 2009).
- The role of peer (other patients or other lay people) is becoming more and more central in the care management. In literature, it is well established the role that peer exchanges and peer support groups have on the management of chronic disease, such as diabetes, cancer or cardiac diseases (MacPherson, Joseph, & Sullivan, 2004). It's obvious that Internet makes these kind of exchanges easier. The advent of Web 2.0 and has offered even more potential than the Internet alone by particularly encouraging participation. According to web (2.0) aim, patients really became the protagonists of their care management; they can construct new knowledge about their illness, their care and their identity and they can have a role in the health care decisions.

1.4 Online peer exchanges related to health issues: state of the art

In Italy the 48,1 use a social network. The use of the social networks is not just connected to the creation and maintenance of friendships, but also social network are

³ The web 2.0 concept and its features will be discussed in the next paragraph.

tools that can be used to find information and communicate about social, health and political issues (22,8 % of the Italian Internet users) (ISTAT, 2011, p. 16).

Participation in online peer exchanges is a growing phenomenon, also concerning to health and chronic disease issues. This kind of participation is particularly relevant for the patient empowerment and it's established by the literature; indeed, the perception of being empowered by online peer exchanges is demonstrated for different chronic condition such as diabetes (Oh & Lee, 2011), cancer, fibromyalgia, arthritis (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009), and HIV (Mo & Coulson, 2010).

But what are we talking about? Even if terms like online patient exchanges or peer groups or online patient communities refer to a world that each one of us thinks to know, there is a mass of concepts, definitions and theorization that need to be discussed.

1.4.1 Quick overview of Web 2.0⁴

The first point to clarify regards the term online. In the last years, there was a shift from web to web 2.0; it has totally changed the health communication world.

In order to review and understand contributions in online field we need to clarify what Web 2.0 is.

The advent of Web 2.0 has offered even more potential than the Internet alone by particularly encouraging participation thus fostering online peer exchanges. Using Web 2.0, we consider all the sites that allows people to interact with each other to the website's content, in contrast to websites where people are limited to just reading the information that is provided to them. Tim O'Reily, the inventor of the Web 2.0 term, defines Web 2.0 activities as "participation architecture" (Grivet Foiaia, 2007) because it and its applications are constructed to promote cooperation and sharing among participants.

Thanks to its structure, people (not only web informatics experts) can add content to Web 2.0 without knowing anything about HTML, Java or other softwares (Korica, Maurer, & Schinagl, 2006). This possibility has really increase the use and the potential

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⁴ It is called Web 2.0 in contrast with Web 1.0: "whereas Web 1.0 was focused more on the downloading of prepared information, Web 2.0 transfers the process into communication about the information" (Jahnke, 2008, p. 196).

of the online world (O'Reilly, 2007). So in Web 2.0 people not only find information but they can change and add information.

Even if there is not a shared definition of Web 2.0 due to its own continuing changing, Constantinides & Fountain (2008) proposed a simple and complete definition that shows the main aspects of this phenomenon:

Web 2.0 is a collection of open-source, interactive and user controlled online applications expanding the experiences, knowledge and market power of the users as participants in business and social processes. Web 2.0 applications support the creation of informal users' networks facilitating the flow of ideas and knowledge by allowing the efficient generation, dissemination, sharing and editing / refining of informational content (p. 232-233).

Web 2.0 has two main dimensions to consider: the social one and the technical one (Grivet Foiaia, 2007).

Briefly, let's start considering the social dimension.

Firstly, according to a psychological perspective, Web 2.0 environment is based on (Riva, Pettiti & Uggè, 2007):

- Expressive dimension: user creates content.
- Communicative dimension: each content is available to everyone.
- Communitarian dimension: contents are the result of the interaction and sharing within a community of users.

Similarly, according to a sociological framework, the fundamental concepts that guide the Web 2.0 logic are:

- Production: considering all the possible web activities as a continuum, the poles of this continuum are consumption and production; "in all forms of virtual togetherness, unlike in the consumption mode, users produce something of value to others content, space, relationship and/or culture" (Bakardjieva; 2003 p. 294).
- Participation: Web 2.0 and its applications structure are constructed to promote cooperation and sharing between participants, and "the social and participatory construction of knowledge is paramount" (Eijkman, 2010, p. 174).

Culture: all production and participation processes create new forms of values and culture. According to this, the Web 2.0 is the place of "Vernacular Culture" (Howard; 2008) where culture is available to everyone because there is no more need of institutions for the knowledge passage and because, in this context, culture is not just transferred but also created in the informal online exchanges.

Secondly, there are the technical aspects; they concern with: 1. the programming technologies - that we will not consider in this work, choosing to deal with the more social aspects- and 2. the different applications/tools that are part of the Web 2.0.

The main types of Web 2.0 applications are described in *Table 1.1*.

Label	Definition	Types	Main features
Blog	"the term web-log, or blog, refers to a	- Personal	- Access can be free,
Biog	simple webpage consisting of brief	blog (one	sometimes a registration or
	paragraphs of opinion, information,	authors)	invitation is needed
	personal diary entries, or links, called	-Collaborative	- Usually people in this blog
	posts, arranged chronologically with	blog (many	can share an interest or they
	the most recent first" (Anderson, 2007,	authors)	can have common
	p. 7)		characteristics.
Forum	"online forums provide a virtual	- Forum	- Based on aynchronous text
2 22 2.2.2	environment to conduct discussion	- Bullettin	interaction
	between a defined group" (Burr, &	boards	- Usually enrollment is
	Dawson, 2003);		mandatory
	,		- Really similar to
			collaborative blog
Wiki	"Wikis in general are self-organising		- Aimed to share, build, and
	web-sites, where anyone on the		store knowledge through the
	Internet can edit existing pages and		collaboration of different
	add new documents any time they wish.		authors.
	This means that every reader can		- Really flexible and adapt for
	instantly become an author." (Kolbisch		work a groups.
	& Maurer, 2006, p. 191)		- The most famous wiki is
	_		Wikipedia
Social	"we define social network sites as web-	- Social	- People create relation and
networking	based services that allow individuals to	network sites	exchanges with other people
	(1) construct a public or semi-public	 File sharing 	they don't know directly but
	profile within a bounded system, (2)	sites	who are part of their
	articulate a list of other users with		connections.
	whom they share a connection, and (3)		- Different aims: dating (e.g.:
	view and traverse their list of		Meetic), professional (e.g.:
	connections and those made by others		LinkedIn), friendship (e.g.:
	within the system" (boyd & Ellison,		Facebook or MySpace)
	2008, p. 211)		(Grivet Foiaia; 2007), health
			(e.g.: Patients like me), and
			content/ file sharing (e.g.:
			Youtube for videos, Flickr
			fpr pictures, iTunes and Odeo
			for podcasting.

Table 1.1- Brief description of main Web 2.0 applications

This is just a brief taxonomy, aimed at giving to the reader a general idea of the possibility of Web 2.0.

Practically, every day new forms of Web 2.0 applications are developed.

In the health field "the broad adoption of Web 2.0 tools has signaled a new era of "Medicine 2.0". The support for collaboration within online communities and the sharing of information in social networks offers the opportunity for new communication channels" (Kargioti, Kourtesis, Bibikas, Paraskakis, & Boes, 2010, p. 971).

1.4.2 Online peer exchanges about health: a brief review

After this general overview, we will focus on the online exchanges about health topics between peers (mainly patients).

To examine online patients exchanges requires the use of different theoretical points of view within a quickly expanding literature and within the increasingly complex and continuous evolvement of the Web. Indeed, the literature proposes many different labels such as: online patient communities, online health communities, online support groups, online health groups, online discussion groups, and so on... It is really difficult to understand if they all refer to the same phenomenon or if they consider different perspectives.

The aim of the following pages will be to briefly (but deeply) review the literature about the peer (and more in general lay) exchanges: 1. on health related topics, 2. happening in online contexts.

Even if the pragmatic relevance of this phenomenon is well established, it's not really clear what we are talking about!

We think that a enough clear (even if broad) definition of what we want to consider is the following: exchanges within "online environments in which users interact with one another around a set of common interests or shared purpose related to health using a variety of tools including discussion boards, chat, virtual environments, and direct messaging" (Newman, Lauterbach, Munson, Resnick, & Morris, 2011, p. 342).

Actually, literature about online peer exchanges concerning health is really confused because there is a lack of shared labels and stated results.

We will propose some reflections – not exhaustive – to try to make order in this chaotic world and to underline what are the topics and areas that need to be deepened.

1. Is it a relevant topic in literature?

There is a growing interest toward this phenomenon in the last ten years 5 (see *Figure 1.1*).

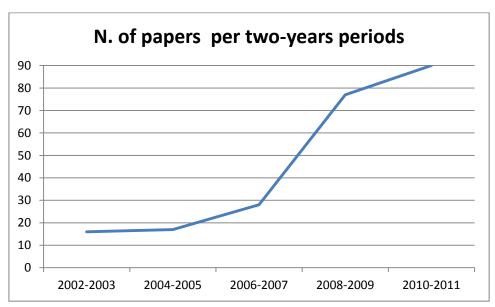


Figure 1.1- Distribution of papers per year⁶

Obviously, this growth is also related to the increasing use of Internet by people in the last ten years. The dramatic increase of literature from the 2008 is surely connected to the advent of Web 2.0 and the possibilities in exchange that it provides.

Because the variety of definition and labels referred to these topics we choose to use the following key terms:

We excluded papers regarding other e-health activities or the use of Internet for health not dealing with peer exchanges.

We considered the last ten years (2002-2012): the use of Internet begun to be part of everyone's everyday life with advent of the new century.

⁵ The figure is based on a literature research about online peer exchanges related to health (using the definition above as a framework) through the electronic databases Scopus, PubMed, Psychinfo, and Google Scholar.

[•] patient + "online community", "online group", "online discussion", "online discourse", "online exchange", "online forum", "blog", "online social network", "web 2.0";

[•] health + "online community", "online group", "online discussion", "online discourse", "online exchange", "online forum", "blog", "online social network", "web 2.0".

⁶ The year 2012 was not inserted in the graph because it's not already finished, but we cosider its article in the review process.

2. Where do the online peer exchanges about health happen?

A shared definition of online exchanges between peers and the context in which they happen about health doesn't exist. The labels used are really different:

- Online community: it is probably the most used label to refer to contexts in which online exchanges happen. Even if the sociological roots of this label (Tackett-Gibson, 2008), a shared definition of this concept can't be find. Practically literature uses this term without giving a clear definition (e.g.: Nelson, Hwang, & Bernstam, 2009). Online communities are also defined as: 1. "online health communities", referring to health as the topic of the interaction; Brubaker, Lustig, & Hayes (2010) states they are "disease-specific communities" (p.1); 2. online patient communities, referring more to the peer dimension of the exchange (e.g. Edenius, 2005).
- Online Group: in particular, self –help (Sandaunet, 2008) or support group (Owen, Yarbrough, Vaga, & Tucker, 2003). These labels take their origin from the psychoeducational approach to health (Skeels, Unruh, Powell, & Pratt, 2010). According to this perspective, online peer groups are useful tool to cope with the illness. Firstly, the interest of the authors in this field was to understand if this kind of intervention could work online (Houston, Cooper, & Ford, 2002) and what was the role of the professional moderator (Klemm, 2012). More and more this label is used also for natural (not constructed for ad hoc interventions) online contexts of exchange in which patients, mainly chronic, meet to find support (Eichhorn, 2008).
- Talk/discourse/narration: this area refers to the linguistic dimension of the exchanges. Main used terms are talk (Veen, Molder, Gremmen, & van Woerkum, 2010), discourse (Miles, 2009) or narration (Overberg, Toussaint, & Zwetsloot-Schonk, 2006). In this perspective peer exchanges are considered in order to understand the social discourse and construction of health and illness, as "the creative possibilities of the web allow individuals to explore the ambiguity inherent in the chronic-illness experience but often glossed over in common cultural tropes about it" (Miles, 2009, p.8).
- Online communication: this is a general term not referring directly to peer exchanges. Anyway, it is used to label patient exchanges. According to this acceptation, no importance is given to the communitarian or group aspects of the peer exchanges (Halliday, & Boughton, 2009).

- Web 2.0 application: many authors (e.g. Im, Chee, Lim, & Liu, 2008) bypass the problem of the definition of the online peer exchanges or the context in which they happen, just talking about the web tool forum (Toscos, Consolvo, & McDonald, 2010), blog (Adams, 2007), social network (Ma, Chen, & Xiao, 2010) supporting the considered exchanges. This type of approaching the question is connected to the perspective given to the online exchanges: they are used just as a source/channel to collect information. Even if we just said that one of the way to refer to online peer exchanges about health is to call them by using the application they are based on (e.g. online forum of white midlife women that are experiencing menopausal symptom- Im, Liu, Dormire & Chee, 2008), not real attention is given to the type of application who support the exchanges. Actually, we find online peer exchanges about health supported by many different types of Web 2.0 applications, but no attention is provided to the way in which the different tools can frame or influence the exchanges.
- 3. What are the main questions in the study of online peer exchanges about health? It's possible to say that literature about online peer exchanges concerning with health is aimed by four main types questions:
- To describe/detect the content of the exchanges. As already said, the exchanges are used as mere source of contents, mainly about patients' identity (Gajaria, Yeung, Goodale, & Charach, 2011), their conception of illness (Leggatt-Cook, & Chamberlain, 2012), their coping strategies (Cavaglion, 2008), the judgments about therapies and drugs (Cain, & Dillon, 2010) and the topical phases/moments of the illness (Copelton, & Valle, 2009). In fact, the main used research method for the study of peer exchanges in health is the content analysis (e.g. Bondy, & Bercovitz, 2011). A lack of literature concerns the ways in which these contents are created.
- To understand motivations and benefits in the participation in online peer exchanges. The interest is toward the reasons why people participate into peer exchanges about health (Tanis, 2008) and what are the perceived benefits (Hess, Weinland, & Beebe, 2010). Substantially people use these exchanges to gain useful information (Nettleton, Burrows, & O'Malley, 2005), to find social and emotive support (Bar-Lev, 2008), and to share knowledge and experience (Graffigna, Libreri,

- & Bosio, 2012). Again the focus is on the outputs and not on the ways in which these knowledge and support are constructed.
- To define types of participants into online peer exchanges. In order to answer to this question, big attention was given to the differences in gender (Ginossar, 2008), age (Chou, Hunt, Beckjord, Moser, & Hesse, 2009), and race (Im *et al.*, 2008) between participant in the online peer exchanges.
- To study the interactive processing of the online peer exchanges. A little area concerns with the ways in which the exchanges work, mainly considering: discursive and conversational aspects (Vayreda, & Antaki, 2009); types of messages (Falcone, 2010); network of interactions using social network analysis (Chang, 2009). This is a little branch that need to be more considered.

4. What are the diseases mainly considered by the literature?

The study of online peer exchanges about health concerns with a great variety of health conditions, mainly chronic (Weinert, Cudney, & Hill, 2008). Between them, "the vast majority address cancer" (Lieberman, 2008, p. 2447) — mainly, breast cancer (Setoyama, Yamazaki, & Namayama, 2011) and prostate cancer (Sillence, & Mo, 2012). Branchs of studies towards online peer exchanges about other chronic conditions, such as diabetes (Oh et al., 2011), mental health issues (Webb, Burns, & Collin, 2008) and depression (Hausner, Hajak, & Spiessl, 2008), HIV (Mo, & Coulson, 2010) have been quiet developed. It's also really interesting to notice that peer exchanges are use in the management of bad habits, such as alcohol abuse (Cunningham, van Mierlo & Fournier, 2008) or smoking (Shahab, & McEwen, 2009), and promotion of healthy behaviors, such as physical activity (Richardson et al., 2010) or healthy diet (Baghaei, Kimani, Freyne, Brindal, Berkovsky, & Smith, 2011).

5. Who are the actors who participate in the online peer exchanges?

It's interesting to notice that even if usually literature in the topic considers online peer exchanges between patients (e.g.: Adams, 2011), a growing number of contributes is focused on peer exchanges between caregivers (Tanis, Das, & Fortgens-Sillmann, 2011) who need support and information exactly as patients. Moreover little attention is given

to the general lay public (Miller, & Pole, 2010): in this case people are just interested in health issues, even if they don't experience illness.

1.5 Concluding remarks: what challenges for the online peer exchanges about health issues

In this chapter we reflected on the role that the Internet has in the health care management.

We understood that the use of the Internet by patients is really outstanding and varied; in particular, online peer exchanges, more and more central thanks to the advent of Web 2.0, allow people to find support, information and to share with the others experience and knowledge useful to their care management; indeed, patients are not just passive actors exposed to information, but they actively participate in constructing knowledge about the topic they are discussing about.

Even if the relevance of this phenomenon, there is a big gap in the literature. In fact, even if it's clear the role of patients as constructor of knowledge in online environments (O'Grady, Witteman, & Wathen, 2008), there is no attention on how these patients construct their information, knowledge and culture online.

As we stated in the last paragraph, the interest of research about online peer exchanges about health issues is mainly focused on the contents and the knowledge that is produced by the exchanges and not on the knowledge production or construction processes.

In our opinion, there are at least two main questions that need to be answered:

- How does knowledge sharing and construction happen in online patient exchanges?
- How does the online environment and its different possibilities (e.g. different Web 2.0 applications) shape knowledge sharing and construction?

The next chapter will give an overview of a research project aimed to answer to these questions.

Then chapter 3, 4, and 5 will show each step of this research.

Quick legend

Because of the variety and confusion between labels concerning online peer exchanges about health, before to start the presentation of the project, we want to give some definitions of the main key terms that are used in this work:

- Online context: it is the environment in which online exchanges happen. According to Galimberti (2011) online context is composed by: 1. "cyberspace" that comprehends: a. the material context (the physical net), b. the digital context, namely the set of the different Web 2.0 application that is possible to find online, c. the effects of their interactions; 2. "cyberplace" refers to community places, born thanks to new digital technologies, defined by social and shared meanings, and by the symbolic dimension of experiences lived by the subjects within these cyberplaces. So online context has defined by both technical and social dimensions.
- Online application: it refers to "services (or user processes) built using the building blocks of the technologies and open standards that underpin the Internet and the Web" (Anderson, 2007, p.7). Substantially they are technical platform for online contexts.
- Online interaction: it is a discursive phenomenon (Zheng, & Spires, 2011) that
 happen in a specific online context in which two or more people talk together
 by using texts, but also pictures or video (Herring, 2010).
- Online exchange: it is a broader concept (than interaction) as it comprehends non only discursive phenomenon but also the possibility to send someone a content by e-mail, or to share a content by social networks tools, by peer-to-peer sharing and by social bookmarking (Anderson, 2007).
- Online knowledge processes: it refers to all the different types of transferring, sharing and building of knowledge considered in the literature. In chapter 3 we will provide specific labels and definitions for these processes according to the different theoretical options.

CHAPTER 2

The research project

In the previous chapter we presented the state of art of literature about online peer exchanges concerning health, underling the importance to understand how people construct knowledge about their health by online peer exchanges. This chapter will present a research project aimed at anwering this question. This chapter describes the case, the aims, the plan of the research and the methodological approach.

2.1 The research case

As we already said, literature clearly stated the relevance of the online peer exchanges for different chronic conditions (see chapter 1, paragraph 1.4). The motives to use online peer exchanges about a specific chronic condition remain the same in many different condition: find useful knowledge to manage the disease and gain social and emotional support. For example, Chen (2012) compared contents of online support groups about breast cancer, diabetes and fibromyalgia and he found similar categories, such as support, experiential knowledge, treatments/procedures, medications, and condition management, in all the groups.

According to these assumptions, we present a research case focused on the online peer exchanges between diabetic patients in Italy.

2.1.1 Diabetes

Across chronic disease, **diabetes** appears a paradigmatic in case.

Firstly, diabetes is a really relevant problem in terms of world health. It is a chronic disease that affects around the 10% of the world population (World Health Organization, 2011): across the world around 220 million people have diabetes (Kneck, Klang, & Fagerberg, 2011). It has consequences (such as stroke or renal failure) that can converge on the death of the patient (World Health Organization, 2011).

Secondly, diabetic people have to drastically change their way of life. Practically, "diabetes, which takes two main forms, is a condition whereby the amount of insulin produced in the pancreas is insufficient to control the level of blood glucose [...]. Consequently, from a biomedical perspective the management of a diabetic condition requires compliance with a regime designed to achieve optimum blood glucose levels" (Loader, Muncer, Burrows, Pleace, & Nettleton, 2002, p. 54).

Diabetes is divided into:

- Type 1 "the body can never produce insulin again. That's why people with Type 1 diabetes must get insulin from daily injections or an insulin pump" (Parker, 2008, p.8). This type of diabetes is usually diagnosed in childhood (it's also called juvenile diabetes):
- Type 2 "the body loses the ability to efficiently use insulin produced by the pancreas. [...] More and more insulin is required to move normal amounts of sugar into the cells. Your pancreas may be able to make more insulin to keep sugar moving from the blood into your tissues for a time, but eventually it just can't keep up, and the amount of blood sugar rises, causing Type 2 diabetes" (Parker, 2008, p.9). Obese people and elderly usually suffer from this type of diabetes.

In order to keep their disease under control (MacPherson, Joseph, & Sullivan, 2004) and to avoid diabetes consequences, such as retinopathy and neuropathy (Hoffman-Goetz, Donelle, & Thomson, 2009), both types of diabetic people need numerous behavioral

changes, such as diet, physical activities, adherence to the treatments. If well-controlled, diabetes allows a "normal" life (not disabling).

This means that diabetes involves everyday behavior and daily management of care (Kneck, Klang, & Fagerberg, 2011), and diabetic patients have to be active and attentive in their daily care (MacPherson, Joseph, & Sullivan, 2004).

Thirdly, it's well established the role of peer groups in managing diabetes because they give the opportunity to diabetic patients to receive feedbacks and suggestions about their care behaviors (Christie, Romano, Thompson, Viner, & Hindmarsh, 2008) and to share knowledge and experiences (Joseph, Griffin, Hall, & Sullivan, 2001). According to this perspective, the use of Internet and online peer exchanges in diabetes management and education is more and more a crucial source of pragmatic and psychological support for the illness management (Greene, Choudhry, Kilabuk, & Shrank, 2010). A growing field of study about online exchanges between diabetes patients exists, even if it is not so expanded as the ones about cancer or mental health. It focuses mainly on the contents dealt by the patients (Ravert, Hancock. & Ingersoll, 2004) and on the role of the online exchanges in patients empowerment (Oh, & Lee, 2011), but not on the process of exchanging and construction. Similarly, literature presents contributes focusing on diabetes online exchanges supported by forums (Hoffman-Goetz et al., 2009), blogs (Oransky, 2006), social networks, such as Facebook (Greene et al., 2010) or Youtube (Fernandez-Luque, Karlsen, & Melton, 2012), but no attention was given to the role of these different Web 2.0 applications into shape the exchanges and the knowledge processes.

2.1.2 Use of the Internet in Italy

The research was developed in the Italian context. According to the number of Internet users, Italy is ranked 32nd in Europe. Despite that, the number of Internet users in the last ten years is more than duplicated (from 22,8% of the total population in 2000 to 51,7% in the 2010) (Source: www.internetworldstats.com). For its characteristics, it seems a good context in which to understand the online peer exchanges in health: it's a really relevant phenomenon, but there is enough possibility to address these exchanges to make them more supportive for good knowledge sharing processes among patients.

Moreover, we wanted to show some data about the relevance of the topic diabetes in the Italian Web world (*Figures 2.1, 2.2 & 2.3*).

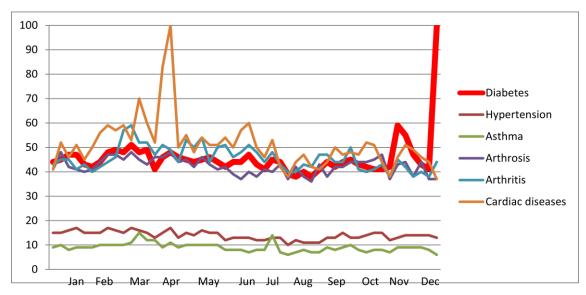
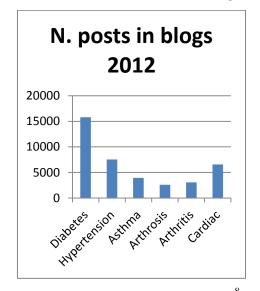


Figure 2.1 - How many people look online for "diabetes" in Italy in 2012 (Source: Google trends⁷)



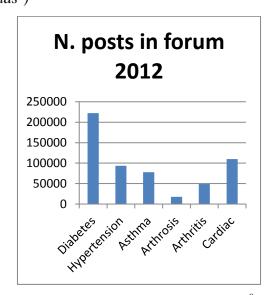


Figure 2.2 (Source: Google Blogs⁸) Figure 2.3 (Source: Google Discussions⁹)

⁹ In this case, we referred to the amount of references detected by Google Discussions.

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⁷Google Trends provide data about people google searching. The numbers on the graph reflect how many searches have been done for a particular term, relative to the total number of searches done on Google over time. They don't represent absolute search volume numbers, because the data is normalized and presented on a scale from 0-100. Each point on the graph is divided by the highest point, or 100.

⁸ In this case, we referred to the amount of references detected by Google blogs.

Figure 2.1 shows how many people in Italy searched online for diabetes in 2012. It's evident that this phenomenon is continuous during the year (it dramatically increased at the end of the year because in November there was the Diabetes Day). Moreover people search for diabetes at least as they search for other chronic conditions (we considered the most relevant according by ISTAT¹⁰).

Figures 2.2 and 2.3 show the number of posts, respectively in blogs and forums, including the word "diabete" (the Italian word for diabetes). It's evident how diabetes is a hot topic in online discussion, much more than other chronic conditions.

These descriptive background data state the relevance of the diabetes in the online Italian world and the necessity to understand if and how people use this tool to construct knowledge about diabetes and its management.

2. 2 The research purposes and aims

This work wants to deepen the study of the online knowledge sharing and construction¹¹ processes between peers about diabetes in order to understand how they work, what their progression is and which conditions (both social and technical) of the online contexts can foster or hinder it.

This research has two main purposes:

1. **Purpose one:** The **context** in which the knowledge sharing and construction happens. As described in chapter 1, Web 2.0 context has both social and technical features; and it is very heterogenic both in its technical aspects (as it is composed of blogs, forums, wikis, social networks and all the emergent social medias) and social aspects (ways of participation, actors, usages and practices, trust). Even if technical specificities of each Web 2.0 application are very well defined (Korica, Maurer, & Schinagl, 2006), there is a lack of literature about the role that these different applications may have in configuring patients online exchanges and knowledge processes. Moreover, a shared definition of the social aspects that can shape

¹⁰ For more information about chronic disease in Italy see:

http://dati.istat.it/Index.aspx?DataSetCode=DCCV_STATOSALUTE&Lang=

¹¹ The label knowledge sharing and construction has been chosen on the base of the theoretical approach that guide this dissertation. It will be explained in Chapters 3 & 4.

different online contexts, in particular in the health field, doesn't exist. According to this premise, the two aims and corresponding studies for this first purpose are:

a. Study one (Chapter 3): MAPPING WEB 2.0 CONTEXTS OF PEER EXCHANGE ABOUT DIABETES

Aimed to **map the online contexts about diabetes**, defining their main features both technically (e.g., types of Web 2.0 applications, types of exchanges activities allowed by the application) and socially (e.g., actors, type of participants, trust toward the online context and the others) and contents (the words exchanged), considering if and how different online contexts may shape different knowledge processes.

b. Study two (Chapter 4): 2- IDENTIFYING SOCIAL AND SITUATIONAL INGREDIENTS FOR "IN A TOP SHAPE" ONLINE CONTEXTS

To define what social and contextual **conditions** (e.g., demographics, membership, aim, boundaries, type of enrollment) **create an online context able to support and facilitate knowledge sharing and construction about diabetes**. Once we have found the online contexts that allow knowledge sharing and construction processes, we want to focus on those contexts understanding their role in the progression of knowledge sharing process.

- 2. Purpose two: The process (e.g.: temporal, discursive, conversational) of the online knowledge sharing and construction between diabetic patients. Literature about online peer exchanges in health focused mainly on the outcomes (contents and knowledge produced) of exchanges and not on the ways in which these outcomes are constructed. The aim and corresponding study for this second purpose is:
 - c. Study three (Chapter 5): ANALYZING KNOWLEDGE SHARING AND CONSTRUCTION PROCESSES

To deepen the study of knowledge sharing and construction processes about diabetes. We want know how people share and construct knowledge helpful in their daily management of diabetes. In particular, we are interested to explore if different processes exists and what they are and to define their phases, their discursive strategies, and their contents.

2.3 Research plan

According to the previous paragraph, we developed three studies (Figure 2.4). Each study is focused on a single aim.

Study 1- MAPPING WEB 2.0 CONTEXTS OF PEER EXCHANGE ABOUT DIABETES

aimed to take a picture of online diabetes-focused exchanges contexts, considering how and if different online contexts may shape different knowledge processes and identifying online contexts where knowledge sharing and construction happens.

Method

Systematic exploration, collection and analysis of Web 2.0 sites hosting exchanges about diabetes

Study 2- IDENTIFYING SOCIAL AND SITUATIONAL INGREDIENTS FOR "IN A TOP SHAPE" ONLINE CONTEXTS

ed to define the social and situational features of online contexts that favor or hinder interactions and knowledge sharing and construction processes about diabetes.

continuing observation of online contexts that seem (Study 1) the more able into support knowledge sharing and construction in order to built a taxonomy of the contexts features that may shape knowledge sharing.

Study 3- ANALYZING KNOWLEDGE SHARING AND CONSTRUCTION PROCESSES

aimed to understand the main type of knowledge sharing processes and to define their phases, their discursive strategies, and their contents.

Method

Use of a grid for analysis to comprehensively study these processes

The grid comprehends the following areas: - Temporal development;

Interactive dynamics (conversational and discursive) aspects;

-Content; - Multimodal analysis;

Figure 2.4- Research project schematic

The research plan is funnel-shaped; indeed, we start from considering all the online contexts dealing with diabetes and then we focus more and more to those contexts able to support knowledge sharing and construction processes and to the processes theirselves.

Chapter 3, 4 & 5 will respectively present theoretical underpinnings, methodology and results of Study 1, 2 & 3.

The following paragraph will focus on the methodological frame of the all research project.

2.4 The methodological approach

All of the studies are guided by an ethnographic perspective. We will presents the basic features of this approach, its application to the online, and discussing why we chose it.

"Ethnography is not one particular method of data collection but a style of research that is distinguished by its objectives, which are to understand the social meanings and activities of people in a given 'field' or setting, and its approach, which involves close association with, and often participation in, this setting." (Brewer, 2000, p. 11).

Ethnography is considered one of the oldest qualitative methods (Mayan, 2009). It was born in the anthropological field between the end of nineteen century and the beginning of the twentieth century in order to study populations and cultures physically and socially far away from the western societies (see for example: Malinowski, 1922 or Mead, 1928). Then, moving to sociology, it returned into the western societies and it was applied to particular culture/subculture in any field (health, education, consumption...). Ethnography uses many different data collection tools, some really traditional such as observation (participant or not), field notes or interviews, and other more innovative such as the use of artifacts, visual material or poetry (Mayan, 2009). Moreover it is possible to identify different branch of ethnography, such as focused ethnography (Richards & Morse, 2007) or institutional ethnography (Smith, 2005) or autoethnography (Ellis, 2004). We are not interested to deepen them, but we want underline that ethnography has a really long research tradition, using many different tools and developing many different perspective; even if all these possibilities, the crucial aim is to describe and understand the practices of a particular group.

The development of the Web world really engage the ethnography, creating some different labels (see *Table 2.1*).

Label	Definition
Cyberethnography	"the ethnography of both online and related offline situations, the ethnography of humans and non-human actors in both types of fields" (Teli, Pisanu, &
	Hakken, 2007, paragraph 1)
Digital Ethnography	"New information and communication technologies today provide the opportunity to explore storytelling through multimedia, including video/filmmaking, in what we describe as digital ethnography" (Sandercock, & Attili, 2010, p. 23)
Netnography	"adapts ethnographic research techniques to the study of cultures and communities emerging through computer-mediated communications and uses information publicly available in online forums" (Kozinets, 2007, p. 130)
Online Ethnography	"is a qualitative approach to data collection in virtual communities" (Skageby, 2011, p. 411)
Virtual Ethnography	"is the application of ethnographic methodology to virtual worlds" (Hancock,
	Crain-Dorough, Parton, & Oescher,, 2011, p. 458)

Table 2.1 –Main ethnographic approaches toward online contexts

All these approaches want to apply ethnography principles to the online world, with some differences: cyberethnography, for example is focused on the relationship between online and offline contexts within a certain community/community/culture (Rybas, & Gajjala, 2007), digital ethnography on social media as new form of storytelling (Murthy, 2008), and netnography on online communities (Kozinets, 2010).

Practically, we didn't choose one particular approach: they can be considered as really similar options in terms of aims, tools and research process development. We just say that our research project is informed by an ethnography approach applied to the online world.

Starting from these assumptions, we decided to use an ethnographic approach, considering five main points:

- The topic: figuratively speaking the web world for us can be considered as the Papua New Guinea for Margaret Mead; practically, we are studying a quite new world, where contexts, practices and rules dramatically evolved in the last 20 years and are evolving right now.
- The community framework: literature states the importance to deepen the role of the culture and the social aspects as they frame the knowledge sharing and construction processes (see Chapter 4).

- The explorative aim: the online world is new and changing, moreover the knowledge sharing and construction processes between patients are quite unexplored topics of research. Ethnography is usually aimed to understand unfamiliar phenomena (Mayan, 2009).
- The "emic" perspective: we want to understand the perspective of people that use the Internet in order to share and construct knowledge about diabetes: "the goal of ethnography is to describe the experience from the patients', or the emic, perspective, framing it in the context of study" (Morse, 2012, p.84).
- The methodological flexibility: due to the continuous changing and development of online context, it's necessary use a flexible methodology, such as ethnography, in order to build new tools adapt to the specific context.

We conclude this chapter by briefly reporting some notes about the use of the softwares and the ethics issue that regards all the research project. Definition of data collection, sample and data analysis will be provided specifically for each study.

2.5 The softwares

"Software packages simply cannot do mental work for you. It is always you, as the analyst, who has to do the real analysis. Because only human researchers can think. The software only provides more or less useful assistance and support to the thinking subject" (Konopásek, 2008, paragraph 1)

The analysis was developed by using the support of three main softwares: ATLAS.ti, NVivo10 and T-Lab. We will briefly present their main features and the ways in which we used them.

Firstly, the three softwares shall be divided into two main categories:

• Theory building softwares (ATLAS.ti and NVivo10): "they simply help us to manage them [data]. In particular, computer aided techniques for qualitative data analysis offer some shortcuts for coding, sorting, and integrating the data. In fact, it is through facilitating researchers to manage large quantities of qualitative data" (Rambaree, 2007, p. 3). They make simpler the code and retrieve activities, typical of qualitative data analysis.

• Textbase managers (T-Lab): "are mainly concerned with the quantitative 'content' of qualitative data and automatic generation of word/phrase indexes, statistical information on word frequency and the retrieval of text in context" (Lewins, 2001, p. 304).

We used the software as follow:

- 1. to store and manage data: according to the above definition, we used ATLAS.ti and NVivo10 to support and facilitate data analysis. In particular, they were useful for our purposes as they store and systematize big amount of data. In fact we analyzed 156 sites for study 1 and then we monitoring 20 sites in study 2 and we analyzed 7673 post in study 3. At first sight, we chose ATLAS.ti. because it was considered the most popular and easy to use (Rambaree, 2007). This decision was taken in 2010. In the last two years Nvivo and MAxqda became more and more popular (Schönfelder, 2011). Then in 2012, Nvivo has been upgraded to the 10 version, that has strongly improved its ability to store and manage data from online environments: "capture and work with web pages and online PDFs, import Facebook posts, LinkedIn discussions and tweets from Twitter, automatically code social media data quickly and easily visualize the results, work with content like memos, photos and web clips" (QSR International, 2012). Because of these features, this new version of NVivo has been considered the best one for our purposes and we used it to support analysis in study 2 and 3. In fact it really facilitates the practical storage of big amount of data. In terms of support to the analysis (data code and retrieving) we considered the two softwares really similar and we used them mainly because of the possibility to store data.
- 2. To support the content analysis: again because of the big amount of data, we chose T-lab as a tool able to preliminary explore texts, without the need of previous analytical hypothesis (Lancia, 2004). Practically, T-lab, basing on the analysis of lexical units (e.g. word), context units (e.g.: sentences or paragraph), and variables (categories provided by the researcher), creates matrixes that represent relations between the different unites (C.U. and L.U.) and indicates occurrences or co-occurrences of the considered phenomena. Starting from these matrixes, the

software is able to explore measure and map co-occurrences between key-terms by using many different technical options (Lancia, 2012) ¹².

2.6 Ethical issues

Literature is still debating about ethics and its boundaries in the Internet research (Buchanan, 2011), and clear and shared guidelines don't exist about the definition of public and private spaces (Convery, & Cox, 2012), informed consent and not even the definition of an human being beyond the screen (Hine, 2008).

Anyway, considering our data we followed 2 different strategies:

- Study 1: all considered websites "are accessible without any restrictions, they can be characterized as public communication" (Langer & Beckman, 2005, p. 196). According to the communication studies' perspective, we considered all the sites as containers of published information, accessible to everyone and not protected by any privacy law.
- Study 2 & 3: in these two studies we analyzed closed groups. To read contents of these groups, enrolment to them was necessary. Before to enroll, we asked permission to groups' masters. They sent us (by e-mail or Facebook private messages) written permission to observe the exchanges as not participant observer (without participating into the exchanges). All the web masters we got in touch with give us the permission to observe the exchanges in the groups; moreover they were enthusiastic of the project ("Ho letto con interesse e il vostro lavoro sarà sicuramente apprezzato...per entrare nel gruppo non ci sono problemi, provvederò io ad iscriverla" [I read with interest your work and it will be surely appreciated... no problem in order to enter the group, I will provide to enroll you]) Only one of the master we contacted gave us the permission to observe but not to cite the name of the group or people in it and to not use messages or pictures from his group. We chose to not say the name of any of the forums and Facebook groups analyzed. In fact, if we decided to say the name of each group, reported quotes will be easily connected to the person who told them, not respecting his/her personal privacy (even if the message was written in a group we had the permission to study).

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¹² In the methodological explanation of each study we will indicate what analysis options we chose, between the tools provided by T-Lab.

CHAPTER 3

Study one¹³: mapping Web 2.0 context of peer exchanges about diabetes

3.1 Preliminary remarks

This chapter will present the Study 1 of the project, aimed at mapping online contexts of peer exchanges about diabetes in Italy in order to define where (in which online contexts) different knowledge processes can happen.

We will briefly review the state of art about online knowledge process (we refer generally to knowledge process, as many different labels to define processes of online construction of knowledge in literature exist. Next paragraph will explore this topic). Secondly, we shall explain the specific aims and the methodology of this study. Then, starting from scenario data, we will propose the map of the online contexts of peer exchanges about diabetes, explaining what are the two main dimensions on which the map is based and we will locate on the map Web 2.0 applications, content of the exchanges and actors of the exchanges explaining how they are connected. Finally, we

¹³ Study one first findings have been presented and described in:

Libreri, C., Graffigna G. (2012). Mapping online peer exchanges on diabetes. *NeuroPsychological Trends*, 12, pp. 125-135.

Libreri, C., Graffigna, G. (accepted, expected publication date: 2013). How Web 2.0 shapes patients knowledge sharing: the case of Diabetes in Italy. In El Morr, C. (Eds), *Research Perspectives on the Role of Informatics in Health Policy and Management.*

will discuss if and how different knowledge processes are supported by different type of exchanges.

3.2 Knowledge processes: a taxonomy

As we said in chapter 1, literature about online peer exchanges regarding chronic issues (and in particular diabetes) doesn't give any attention to the ways in which patients (and more in general lay people) construct contents and knowledge. In this first paragraph we will move some theoretical steps useful to answer to this question. We need to understand if and how online (and also offline) knowledge sharing and construction processes have been studied - coming out of the health literature - and what theories and models exist. Then we have to understand if these models or theories can be applied to online peer exchanges about diabetes and how.

Briefly, we report the main important processes (their labels and definitions) that concern with a passage of knowledge and the possible construction of new knowledge. We voluntarily use this broad definition because there are a lot of processes studied (online and offline). A brief overview allows to choose the most fitting for our purposes. Three preliminary considerations are necessary:

- even if we looked for the theoretical roots of the following different concepts, we chose to focus our analysis only on their application on the online contexts;
- the aim of this work is not to be an all-encompassing review of all the knowledge
 processes that happen online; we tried to identify and to define the principal
 concepts used according to a psychosocial perspective. Other labels and definitions
 probably exist, but we report the main clusters of concepts connected to the
 knowledge passage and construction processes in the online contexts;
- we propose a taxonomy, based on the different theoretical assumptions that usually
 frame the different concepts. Anyway, all the concepts are often used as
 synonymous, even if they refer to processes that really differ (e.g. So, & Bolloju,
 2005).

Firstly, it's necessary to state what we mean using the word knowledge. We choose to talk about knowledge and not about information, even if literature regarding knowledge processes (in health or in other fields of study) often use this two terms as synonymous.

According to Baran and Calgitay (2010) "information is unprocessed content that needs to be cultivated by human beings into knowledge" (p.155); instead knowledge is "that which we come to believe and value on the basis of the meaningfully organized accumulation of information (messages) through experience, communication, or inference" (Zack, 1999, p.46). These definitions make us notice that: 1. knowledge is constructed and configured according to the culture and the experiences of both giver and receiver (Sharratt, & Usoro, 2003): "knowledge is significant only in its collective or social framework" (Leung and Chan 2007, p. 54); 2. this knowledge is strictly connected to the real experience of the participants in the exchange (in the patients case, knowledge is connected to their management of illness). So the knowledge is something really connected to the social and cultural context in which it is created and it has a strong applicative dimension (Erikson & Rothberg, 2011). In the case of chronic patients the knowledge concerns with the social construction of their illness, of their care&cure, of their identity as patients and with all the practices connected to them.

As we said, there are a lot of terms used to define different "movements" of knowledge. The following table (*Table 1*) is an attempt to show and to define the main used labels and their features.

Label	Main field of	Actors and	Definition	Features
	study	relations		
Knowledge absorption	Education	Individual	"Mechanisms used by scholars to absorb and apply knowledge such as pursuing an academic degree, attending online courses, doing tests in labs, applying knowledge in new settings, and so forth. Absorption refers to using the knowledge acquired; it does not mean to create new." (Echeverri, & Abels, 2008, p. 149)	- Scholar approach - Focus on the individual - Applicative dimension
Knowledge acquisition	Education	Individual	"Brings to mind the activity of accumulating material goods. The language of 'knowledge acquisition' and 'concept development' makes us think about the human mind as a container to be filled with certain materials and about the learner as becoming an owner of these materials. (Hamilton, Dahlgren, Hult, Roos, & Söderström, 2004, p. 848)	- Objective (learning) approach - Focus on the individual

Knowledge	Education	Peers (mainly	"Collaborative knowledge building	- Social and
building		students) with	defines a useful paradigm for	group
8		a moderator	conceptualizing learning as social	practice
		or a	practice in which shared knowledge	- Use of
		facilitator	is constructed [] as the result of	artifacts
		lacintator	inter- related group and personal	- Focus on
			perspectives." (Ang, Zaphiris, &	contextual
			Wilson., 2011, p.539)	features
			Wilson., 2011, p.555)	- Ad hoc
				built context
Knowledge	Internet studies	Peer	"Knowledge collaboration is defined	- Less used
collaboration	internet studies	1 661	as the sharing, transfer,	- Focus on
Conaboration			recombination, and reuse of	trust
			knowledge among parties.	trust
			Collaboration is a process that	
			allows parties to leverage their	
			differences in interests, concerns,	
			and knowledge. Knowledge	
			collaboration online refers to the use	
			of the Internet (or Intranet) to	
			facilitate the collaboration."	
			(Jarvenpaa, & Majchrzak, 2010, p. 774)	
Knowledge	Education	Peers (mainly	"Knowledge construction [] is	- Focus on
construction		students)	based on the assumption that	the discourse
		(with a	individuals engage in specific	- Focus on
		moderator or	discourse activities and that these	the process,
		a facilitator)	discourse activities are related to the	mainly in its
			sharing and negotiation of	individual
			knowledge" (Hew, & Cheung, 2010,	dimension
			p. 304)	~
Knowledge	Education,	Peer, mainly:	"Knowledge creation refers to	- Social
creation	organization	work groups,	developing new content or replacing	practice
	and	companies,	existing content; the above activities	- Focus on
	management	organizations,	are performed through the	innovation
	studies	(van Aalst,	conversion between two types of	
		2009)	knowledge – tacit and explicit	
			knowledge [] knowledge creation	
			involves the conversion from existing	
			knowledge to new knowledge"	
			(Chou, Min Chang, & Lin, 2010,	
To Comment'	Interest of 1	Danii	p.557)	Card 1
Information/	Internet studies	Peer	"When information diffusion in the	- Social
Knowledge			blog world is analyzed, the	network
diffusion			information diffusion paths can be	(Yan, &
			found. In social network theory,	Yang, 2009);
			information diffusion in the social	- Analysis of
			network is said to occur through the	structure and
			established relations between	pathways
			members" (Kwon, Kim, & Park,	- Mere
			2009, p.28)	movement of information
Knowledge	Internet studies	Peer	"Mechanisms used by scholars,	- Focus on
dissemination	michiet studies	1 001	libraries, and publishers to	knowledge
dissemination			communicate the new knowledge	possess;
			created such as posting documents	- Mere
			on the Web, publishing articles in a	movement of
			journal, publishing new books, and	information
	l	j	Journal, publishing new books, and	mormanon

	T	T	T	ı
Knowledge	Health and	Expert and	so forth. Dissemination implies to make new knowledge accessible to other people so they can acquire it to begin again the cycle and doing that, to move forward the topic under consideration." (Echeverri, & Abels, 2008,p.149) "Mobilization theories highlight how	- Focus on
mobilization	political communication	lay people	the Internet can facilitate activities with a political purpose, or how the Internet forms a 'political playground' where people can exercise civic skills and obtain the knowledge deemed important for political participation" (Hirzalla, van Zoonen, & de Ridder, 2011, p. 2)	knowledge possess - Knowledge considered as power
Knowledge production	Communication and political studies	Peer	"The production of knowledge is no longer controlled by social elites thanks to the diffusion of the Internet. Web 2.0 applications, which not only allow but encourage individuals' production and sharing of their own information, break the bureaucratic monopoly of knowledge." (Wei & Yan, 2010, p. 239)	- Focus on knowledge possess - Mere movement of information
Knowledge sharing	Education and organizational studies	Peers that usually share the same role (all students, all colleagues)	"Knowledge sharing refers to the transmission of knowledge between people" (van Aalst, 2009, p. 260) "Knowledge sharing is the process where individuals mutually exchange their (implicit and explicit) knowledge and jointly create new knowledge" (van den Hoof et al., 2003, p.121)	- Social practice - Collaborative practice - Focus on motivations to share
Knowledge transfer	Health (mainly health communication and promotion)	Expert to lay people and decision makers	"Knowledge transfer can be defined as the activity of transforming knowledge into a format which can be used to improve clinical practice and service delivery" (Wilkinson, Papaioannou, Keen, & Booth, 2009, p. 118)	- From scientific actors to lay actors - Focus on the improvement in the management of health and social issues
Knowledge translation	Health (mainly health communication and promotion)	Expert and lay people	"Knowledge translation is the synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people's health" (Arnold et al., 2007, p. 1047)	- From scientific actors to lay actors - Focus on the improvement in the management of health and social issues

Table 1 – Knowledge processes taxonomy

The variety of definitions reported in *Table 1* claims for some reflections.

Firstly, even if all the labels and definitions derive from contributes referring to online group or peer conditions, some of them refers to processes and activities that happen neither in the online context nor in a peer group, but they consider individual processes of elaboration of knowledge (such as *knowledge absorption*).

Moreover, the presented concepts refer to three different disciplinary areas: health, internet and communication, and learning processes (in education and in organization studies).

Looking to the different definitions is clear that the process we are looking for are the ones dealt by learning field.

Indeed, even if we are talking about patients, it's quite clear that health field ones are not the processes we're interested in. The traditional interest of health field to knowledge processes is focused on the comprehension and improvement of the passage of knowledge from the scientific and medical world to the lay world. Health research always tries to find solutions to improve people's health and life but too often the communication of the research results don't reach interested people and health decision makers. Web is a way to connect health world with lay people, showing them what they shold do to solve their problem (Curran-Smith, Abidi, & Forgeron, 2005). One of the research branch in the knowledge transfer and translation area is the development of web portals where different actors, such as researchers, health professionals, policy makers, patients and caregivers can meet (Turnbull *et al.*, 2009), and where experts can propose to patients and caregivers solutions to their health issues and understand patients' needs.

The Internet and communication studies' approach mainly refers to peer dimension. In this perspective is really important to underline how, thanks to web 2.0, the knowledge is more and more constructed and owned by lay or common people (Baez, Mussi, Casati, Birukou, & Marchese, 2010). Anyway this perspective differ from we're thinking about the processes concerning the knowledge; there isn't any interest about the ways in which the knowledge is constructed and produced; the focus is the possibility to disseminate knowledge to the most possible people to give more power to more people (Wei, & Yan, 2010). For some authors this kind of processes deal more

with the information than the knowledge: "while information has become very easy to transmit and store over great distances, knowledge is still difficult to transfer" (Bos et al., 2007, p.653).

Finally, the learning studies focus on how people acquire and construct knowledge. Considering the taxonomy above, we are interested in those approaches who consider learning as a processes happening in a group of peers and aimed to give to them useful knowledge. In this way the concepts knowledge building, knowledge construction, knowledge creation and knowledge sharing can be considered as appropriate to label the processes we are interested in.

Even if it was possible to define the processes we are interested into, some points need to be deepen:

- Firstly, this variety of labels and concepts is symptom of a major focus on the outcomes of these knowledge processes and not on their process of development.
- Secondly, dimensions that configure, support or impede or shape the online knowledge processes are unclear.
- Finally, even if all these definitions refer to the online environment, this dimension is not really considered. A better consideration on the role played by Web 2.0 (in its different applications) in shaping knowledge processes is needed. In fact, for example in the education field, there is an interest into the comprehension of the functioning of online knowledge processes such as knowledge sharing and construction (e.g.: Zenios, 2011) but these processes are studied especially by using forums and discussion boards (e.g.: Nor, Razak, & Aziz, 2010) (considering them as representative for all the Web applications) and no attention is given to the tool of exchange.

3.3 Aims

According to the previous paragraph, the main aim of this study is to provide an overview of the online contexts in which exchanges about diabetes happen, in order to understand what kind of knowledge processes they activate and defining possible online contexts for the development of knowledge sharing and construction processes.

Practically, this inquiry wants to understand what is the role of Web 2.0 contexts into shape different knowledge processes about diabetes in the Italian context by a systematic exploration of these exchanges, focusing in particular on:

1. The online context itself

- a. Descriptive features of online contexts (such as their topic, the information provided by the context itself, the number of participants)
- b. Web applications and their features (such as types of exchange activities allowed)
- c. Social features of the online contexts (such as trust indicators)

2. The exchanges supported by the online contexts

- a. Who are the different actors involved in these exchanges?
- b. What the differences in the contents in these exchanges?

3.4 Method

3.4.1 Data collection

According to the ethnographic perspective, we decided to explore online world by assuming Internet users' perspective.

The first step was the search and the identification of the Web 2.0 contexts in which sharing, participation and discussion about diabetes were possible. A sample of Web 2.0 sites, were found using the Google, Yahoo, Google discussions, Google Blog, and Facebook search engines. We chose Google and Yahoo because they are the most used search engines in Italy. Google Blog and Google discussions were added to pay as much as possible attention on Web 2.0 sites. Additionally, we included Facebook as it is the main social network in Italy.

Our search included only Italian sites: keyword is the Italian word for Diabetes [diabete] and we used Italian version of the search engines (e.g.: Google.it).

The search was performed from February to September 2011.

Then the first 100 references for each search engine (excluding Facebook search that had less references) were analyzed to yield 344 references (in many cases, we found the same references in more than one search engine).

3.4.2 Data analysis

According to the aims of this work, we developed three main steps of analysis. The analysis was based on ad hoc grid, in part developed by theory and in part, inductively developed from the initial analysis.

The first step of analysis regarded the online contexts. It described both technical and social features of the online context as "analyzing a social network Web site gives access to two kinds of information: Web site characteristics, since the social network could not exist without a Web site, and information about the social community made available on the Web site" (Orizio, Schulz, Gasparotti, Caimi, & Gelatti, 2010, p. 1061). The grid had the following sections and items:

- 1. *General description of the website*. Starting from the user perspective, we considered the basic description of the website:
 - a. The main topic dealt by the web site: 1. focused on a specific topic (e.g.: usually diabetes, but also other topics, such as cooking or swimming); 2. an health portal/site; 3. any specific topics.
 - b. Website size described by: 1. number of visiting people; 2. number of enrolled people. Literature considered it as indicator of Web 2.0 site health (in terms of site production) (Chiang, Huang, & Huang, 2010).
 - c. The role of diabetes in the website described by: 1. number of posts/articles and of interactions about diabetes; 2. length of talking about diabetes (practically, we considered the date of the first post about diabetes posted in the context); 3. diabetes connected area: we categorized if diabetes was the topic of: the whole site, a specific section, a thread, a single post/discussion.
- 2. *Technical features* in order to understand if different technical possibilities can shape the exchanges:
 - a. <u>Type of Web 2.0 application</u>: blogs, personal blog, forums, chat, Q&A sites, social networks (during the development of the analysis dived into: social network pages and social networks groups as they have different features)
 - b. Types of exchange activities allowed by the website (this topic was data driven): 1. the possibility to write posts and comments; 2. the possibility to share the contents with other people outside the website by e-mail or by

social bookmarking; 3. the possibility to "like" the posts (directly on the website or on other social networks, such as Facebook); 4. the possibility to quote others' posts.

- 3. Social features based on two main areas of analysis
 - a. <u>Trust indexes towards the site</u> (Orizio *et al.*, 2010). From users' perspective it is really important to have elements that allow to verify who manages the website and guarantees the credibility of the information proposed. Practically we considered as trust indexes:
 - i. The affiliation of the site, considering if it is linked to: 1. some type of health organization (such as hospitals or patients associations), 2. patients (singles or groups of); 3. communication agencies (such as web communication agencies, or blog editorial staffs); 4. no affiliation.
 - ii. Indexes of affiliation; elements that allow to clearly detect the affiliation of the website (Eysenbach, 2005). They were: 1. the presence of a logo;2. the presence of the copyright; 3. the presence of contacts/references; 4.the presence of the name of the admin of the website.
 - iii. Other site trust indexes (Orizio *et al.*, 2010) that help people to have information on the website and its contents: 1. links to other websites/materials connected; 2. admin/authors profile or bionote; 3. mission of the web site.
 - b. <u>Information toward other participants</u>. This area is based on the idea that the possibility to exchanges and the credibility of the contents are also guarantees by the knowledge of the others participants (McKenna, & Seidman, 2005). We considered:
 - i. The type of enrollment required: 1. mandatory enrollment, 2. possibility to participate to the exchanges as host, 3. optional enrollment, 4. no enrollment.
 - ii. Information presented in the profile (adapted from Riegelsberger, Sasse, & McCarthy, 2005 and data driven): 1. Name/nickname; 2. possibility to attach picture or images; 3. presence of socio-demographical information; 4. presence of information about participation to website's activities; 5. link to Facebook or other social networks profile.

iii. Information required to post something (data driven): 1. just enrollment information; 2. name/nickname; 3. e-mail address; 4. Facebook or other social network contacts; 5. no information requires.

Secondly, we analyzed the exchanges about diabetes that were developed in the websites. Also for this step we developed a grid focused on three main areas

- 1. Descriptive features, focused on:
 - a. Lasting.
 - b. Number of posts.
 - c. Number of participants.
 - d. Exchange mode, as different mode can influence the type of exchange (Baker, 2008). We considered: 1. just text, 2. pictures, 3. videos, 4. links.

2. Participants in the exchanges:

- a. <u>Types of participants</u> (data driven): 1. patients; 2. caregivers; 3. presence of one or more experts; 4. others interested in diabetes (but not patients or caregivers); 5. not possible to define.
- b. <u>Information toward other participants</u>. As already said, information towards other participants allow the construction of trust and the will to participate to the discussion. We considered (Green, 2007):
 - i. Chance to verify others' identity by: 1. presence of profiles; 2. information from the site; 3. previous exchanges; 4. shared friends; 5. contacts in the real world.
 - ii. Features in common with other participants, such as: 1. illness; 2. therapies; 3. socio-demographic features; 4. other interests.
- c. Exchange aims (Ancker et al., 2009). As stated in chapter 1, the online peer exchanges are aimed by 3 main motives:
 - i. Find information.
 - ii. Gain support.
- iii. Sharing experiences.

Finally, content textual analysis was provided using T-Lab software. Contents of exchanges were analyzed, according to the main following variables:

- a. Web applications in which the contents were written.
- b. Actors who wrote the contents.

For the sake of simplicity, the final version of the grid is presented in *Appendix A*.

3.4.3 The softwares

As stated in chapter 2 (paragraph 2.5), we used the software Atlas.ti in order to support the storage of the analyzed online contexts and to facilitate code and retrieve process. (Gatti, & Graffigna, 2009).

Moreover, we used T-lab to develop support content analysis. Main features of T-lab were discussed in chapter 2 (paragraph 2.5).

Between the technical specificities of the software, to analyze the data of this study we chose:

• Specificities analysis: it defines which lexical units (words or lemmas) are the most typical lemmas (over-used lemmas) and which are typically absent (under-used lemmas) in a text subset (defined by a variable) (Graffigna, 2009). This analysis allows determining lexical specificities of specific subsets, comparing it to the entire data corpus or to another subset. Outcomes significance is based on chi-square test. Practically, we used it to compare contents produced: 1. in different web 2.0 applications; 2. by different actors.

3.5 Descriptive data

Of the 344 references found, we considered 156 Web 2.0 sites about diabetes.

We chose to exclude 84 sites that did not allow any type of exchanges (e.g. to post a comment, to share posts or discussions, to link content to/from other sites); 79 sites where exchanges about diabetes happened before the chosen period; 20 sites that were off topic (e.g. animal diabetes,) and 5 sites that were not in Italian.

Table 3.2 shows the typology of Web 2.0 applications found.

	N	%
Blogs	77	51
Personal blogs	14	9
Forums	40	25
Chats	1	0,5
Social networks: pages	12	8
Social Networks: groups	8	4
Q&A sites	4	2,5
TOTAL	156	100

Table 2.1- Types of Web 2.0 applications (frequencies and percentage)

Blogs, forums and social networks seem to be the most used contexts to post something about diabetes; anyway, many different Web applications deal with diabetes.

These data make evident the consistent presence of online peer exchanges about diabetes and the variety of online tools which make them possible.

3.6 The map of online peer exchanges about diabetes in Italy

The qualitative analysis, supported by ATLAS.ti, of the Web sites permitted to define a map of the online peer exchanges (see *Figure 3.1*).

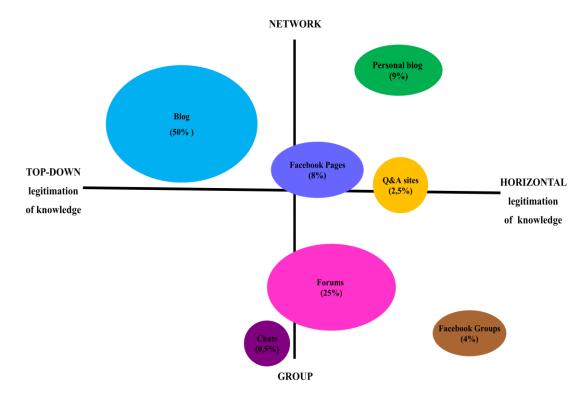


Figure 3.1- Web 2.0 contexts map

This map is based on two main axes:

- 1. Legitimation of knowledge: this axis describes the "model" of knowledge legitimization (i.e. the reliability and credibility of the posts and exchanges contents) in the online context. On the negative pole are described the contexts where there is a "top down" legitimization of the contents and directions, throughout the role of an institutional expert (for example: a health professional, the blog manager...) perceived as a grantor. On the other side, the credibility and usefulness of information shared are guaranteed in a "horizontal" way, by people who participate in the online exchanges themselves. In this "model of legitimization", thus, "expert" is perceived as someone who experienced the problem and its solutions.
- 2. Relational aim: the vertical axis describes the type of linkage sought by patients taking part in the exchange. On the positive pole are positioned all the contexts where patients aim is spreading information within the biggest network of people as possible. In practice, the kind of exchange achieved in these Websites is limited to the posting of news/information and to their forwarding within their reference networks, without adding other comments or knowledge. The other pole is characterized by contexts frequented by patients who seek affiliation and feeling of group belonging. In this case the exchange is animated by, people asking for and sharing opinion, information experiences, within that particular group.

According to the presented map, it's possible to define four main clusters that characterize different type of exchanges and knowledge processes that those exchanges support. The Web applications easily fit into these clusters:

a. *Popularizing*: the aim of exchanges in these sites is to spread information toward the Web, reaching the main number of interested people. The blogs are the main characters of this area. Indeed, blogs are used to share and disseminate information and in particular, news. People do not use blogs to discuss (only 8 blogs presented discussions after the first post). It makes sense, then, that in some blogs (17) people can't discuss about the news or the topic posted, but they can only share with their reference network. The few discussions retrievable in these Websites are limited to the publication of links to other Websites. For example, it is interesting to note that

exactly the same news/information (using exactly the same wording) is posted on many different blogs since those who post do not share personal ideas, but just something they think is interesting or may be useful for their networks. People trust into the expertise and credibility of the ones that manage the blog. Blogs are furnished by many classic trust indexes like logos, copyrights, and contact information. They are mainly managed by Web communication agencies or by experts (e.g., physicians, nurses, nutritionists) that likely need to build trust with people. Many blogs don't require enrollment to post; you can just put your name and e-mail address in order to comment. Only 10 blogs required enrollment to post. Just one blog (autoblog) presented how many people are enrolled and some blogs (19 sites) show how many people have visited the site (this kind of indexe is important for the group construction).

- b. *Exhibiting*: in this area some people or some groups (such as an association) are interested into show information about themselves. This area is mainly covered by social network pages and personal blogs. They are really similar to blogs; one person or group or organization post something about diabetes but there are few interactions. The difference is in the topic. The news doesn't deal some aspects of the disease, but they refer: to a person (personal blog), or to news about projects, associations or organizations to inform/update people that are interested/involved in this project. Substantially they seem display windows: people and organizations use them to show their activities and their interest to the world. For example: the BCD (Buon Compenso Diabete) Facebook page is about a temporary project for diabetes care. The Fondazione Italian Diabete Facebook page is mainly a place where people (e.g., administration, other associations, patients) share information about books, conferences, and scientific papers.
- c. *Educating*: this is the "realm" of health experts. This area is covered by few forums and less blogs in which recognized expert (such as practitioners, nutritionists, psychologists) discuss with people, addressing them towards diagnosis and cure. It's important to underline that when the expert participates in the discussion, the exchange become dyadic and polarized (i.e. expert patient) and the peer exchange tends to be inhibited.

d. Interacting: interaction is "the activity to talking with other people" (Longman Dictionary of Contemporary English, 2001, p.741). Indeed, by using the term interacting we refer to the fact that people are interested into talk with others in that specific online context (see chapter 1, paragraph 1.5). In fact, the aim of this area is to discuss and to share opinions, experiences, emotions and knowledge with other people recognized as qualified (for example for their experience as patients) to say something about the topic. This area is mainly covered by forums and Facebook groups. Here it is possible to track a greater variety of exchange activities: not only related to posting experiences and comments, but also to the possibility to express appreciation for other participants' messages (many forums have tools to express that people like others' comments or to thank or to quote other people's words). Interactions are not only a series of comments but often a person posts something, a second person responds (quoting the first person's words), and the first person provides yet another answer. In fact, in blog interactions the number of posts and the number of participants are the same. In forums, there are almost always fewer participants than posts. This means that participants are involved into the exchange and in the output that this exchange will eventually provide and not only into state their opinion. Moreover, in the forums, people trust toward other participants; there are a lot of indicators that give people information about other participants from which they can evaluate their trustworthiness. For example, in all forums, enrollment is mandatory for participation and in 7 forums, we found enrollment was required to even read the discussion. Other common indicators of trust toward other participants in forum are: the possibility to see each other's profiles (26 sites), a sharing of similar interests (e.g., swimming) (33 sites) and recalling prior conversations/discussions where the person participated (6 sites). Facebook groups are really similar to the forums. People share information and experiences and try to support others. A great example is "Mamme e diabete" where caregivers (mothers) participate in the discussion in order to improve their children care and to support each others. The legitimation of knowledge works similar to forums. People have to be enrolled in Facebook and also in all the specific pages or groups. Further, people have to be accepted to post on these pages or groups. Some groups are closed, so

people have to send a request in order to read the posts. As a matter of fact, Facebook groups present more interactions than forums.

3.7 Contents dealt about diabetes in online exchanges

After, the qualitative analysis of sites and their features, we analyzed the content dealt in the posts and discussion on diabetes by using T-lab software.

According to this analysis, it is possible to show the main relevant – in terms of frequency – contents (see *Figure 3.2*) and to articulate them according to the Web 2.0 applications as described in *Figure 3.1*.

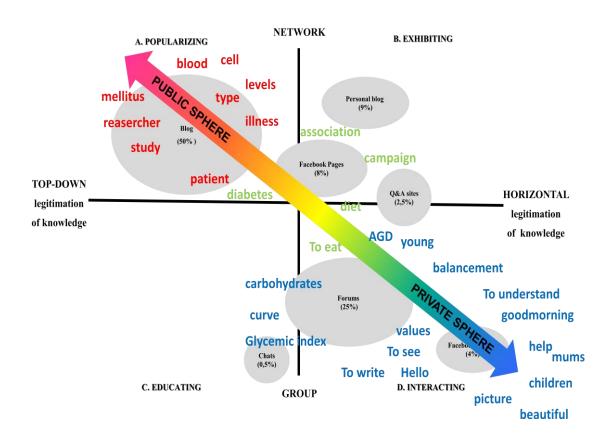


Figure 3.2- Content maps (from T-lab output)

It seems possible to articulate the contents about diabetes covered by online exchanges on a continuum that opposites a "private" to a "public" sphere of meanings and experiences.

The public sphere (especially linked to blogs) is mainly linked to: 1. scientific contents, such as new research or innovation in diabetes care (e.g.: "Associazione tra diabete di

tipo 1 ed enterovirus" [Association between diabetes type 1 and enterovirus] 14) 2. general posts referring: facts, connected to diabetes, happened in the real world (e.g.: "Questo spot, commissionato da FID e realizzato dall'ageniza di comunicazione Armando Testa, ha aperto un'enorme discussion all'interno delle associazioni legate al diabete" [The spot above, commissioned by FID, Italian Diabetes Foundation, and realized by Armando Testa advertising agency, opens a big discussions between diabetes associations]); 3. exchanges to giving/receiving information about diabetes in general, mainly in Q&A sites ("Quale è la differentza tra diabete 1 e 2?" [What is the difference between diabetes 1 and diabetes 2?]); 4. and the diabetes association and group activities, mainly in social networks pages ("Questa è una foto di alcuni degli amici che ci hanno raggiunto in piazza Garibaldi" [This is a picture of some of our friends who joint us this week end in Garibaldi square]).

There is instead a private sphere of diabetes concerning mainly: 1. the daily management of diabetes and all the topic related (devices, food...) (" prova a controllare le impostazioni del bolo wizard, quail valori ci sono e magari puoi alzarli un po' oppute puoi controllare le impostazioni temporali per il rilascio dell'insulina... ora non ho nessuna altra idea" [try to control in the wizard bolus settings what values the device has and maybe you can high them up, or check how much activity time you set for your insulin... now I don't have any other idea...]); 2. and the emotional and social support ("Parlare qui è diverso... ci capiamo totalmente... senza nemmeno vederci!!!!!;)" [To talk here is different. . . . We totally understand each other . . . without seeing us!!!!!;)]).

3.8 Actors of the online exchanges

Finally, posts and exchanges developed by different actors deal with different topics. *Appendix B* shows words specificities considering posts and discussions acted by different actors.

Anyway, it's possible to show on our map the types of participants (see *Figure 3.3*). In practice, different actors activate and participate to different type of exchanges and they focus on different types of content.

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¹⁴ To better explain the meaning of our speech, we added some quotations from the posts analyzed. They are in their original version (Italian) and we provided an English translation. The same type of exemplification will be used in chapter 4 & 5.

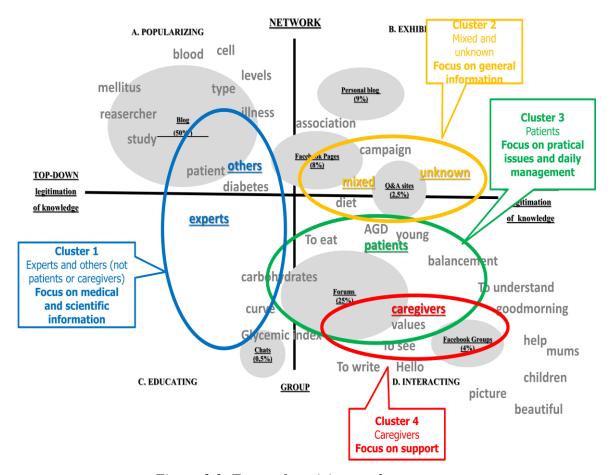


Figure 3.3- Types of participants clusters

Both sites and contents analysis (supported by T-lab) shows four main clusters of participants:

- Cluster 1 (others and experts). The content of the exchanges between these actors is mainly medical and scientific. They deal more with a public sphere of the disease (the left side of the map). As we already said, when some kind of expert (e.g. practitioner, psychologist) participates in the discussion, the exchange is only between a single person and the expert (not between a group). So no knowledge sharing happen, but this kind of process is more similar to a transfer of knowledge in its classical conception: from expert to lay.
- Cluster 2 (mixed). When exchanges happen between mixed actors the focus of the exchanges is informative; we can find two kind of discussion: 1. sharing opinion about a relevant topic ([talking about a TV adv] "Secondo me se non schokki attraverso le immagini e i contenuti, nessuno consider ail tuo spot" [In my opinion

if you don't shock people, in terms of pictures and contents, no one cares about your spot]); 2. asking/receiving general information about diabetes ("Che cosa è la syndrome del piede diabetico?" [What is diabetic foot syndrome?]). These exchanges are positioned between public and private contents (in the center of the map).

- Cluster 3 (patients). Exchanges and posts in this cluster are mainly focused on practical issues and daily management of diabetes. The discussion deals with private contents and it is mainly developed in a problem solving logic. In practice, the discussion is activated by a request to help in solving practical problem ("c'è qualcuno qui cheha il diabete e puo darmi dei consigli? Mi hannodato tutto il material per controllare la glicemia" [is there someone of you that is living with diabetes and can give me some suggestions? They give me all the furniture to check my blood glycemic index...]). They share experiences and knowledge in order to solve a problem.
- Cluster 4 (caregivers). Caregivers mainly exchange support ("Grazie per l'aiuto che riuscite sempre a darmi" [Thank you for the help you always give to me]). Their discussions can be considered as another type of problem-solving exchanges.

3.9 Conclusive remarks

The study allowed the generation of a descriptive framework of online context of peer exchanges about diabetes.

Firstly, different Web contexts make possible different type of knowledge processes. The variety of labels and definitions in literature correspond to different processes and it's fundamental understanding which conditions brings out different knowledge processes.

According to our analysis, two main axes articulated typologies of contexts and processes happening in those contexts.

The first axis ("knowledge legitimation") describes the "model" of knowledge legitimation: vertical is the classical model of knowledge legitimation where an expert proposes, diffuses and discusses his/her knowledge, throughout web based "knowledge transfer" activities (Ekberg *et al.*, 2008). As opposite it's possible a horizontal way of

knowledge legitimation, in which lay actors are experts, since they "experienced the disease". The interest toward the patient "expertise" topic is gaining growing relevance in the health studies (Civan & Pratt, 2007; Civan et al., 2009).

The second axis refers to the "relational aim" that users want to reach: network or group oriented. In a network perspective, the aim is really similar to the knowledge dissemination (Meyer, & Schroeder, 2009) or information and knowledge diffusion (Kwon, Kim, & Park, 2009) processes. According to this view we are "in the age of the Web called liquid. [....] The goal of the model is to disseminate knowledge in the best possible way" (Baez et al., 2010, p.395).

On the other side online peer exchanges are conceived as a way to share and participate in a discussion to construct new knowledge. This perspective directly answers to the idea of O'Reily that considers Web 2.0 participation architecture (Grivet Foiaia, 2007); in these exchanges actors participate in the discussion and they really contribute to construct new knowledge.

This structure makes clear that online contexts of peer exchanges about diabetes may be divide into four main type: popularizing: diffusion and dissemination of knowledge (mainly scientific) produced by someone else; exhibiting: diffusion and spreading of knowledge toward the activities of single individuals or specific group; educating: discussion with experts of relevant topic; interacting: participation into discussions and in the sharing and construction of knowledge useful for pragmatic aims.

According to our results, the type of Web 2.0 context has an important role into shape the knowledge processes; both its technical and social features affect the type of exchanges and knowledge processes developed between patients. In particular the different types of knowledge processes are characterized by:

• Different type of Web applications. Blogs are used mainly for knowledge spread, instead forums support knowledge sharing and construction processes within a group. Social networks have different type of applications that can support different type of processes. In our opinion, Websites that want to sustain exchanges has to join the media richness approach: "the media richness of various technologies is defined by its capacity for immediate feedback, its ability to support natural

language, the number of cues (non-verbal) it provides, and the extent to which the channel creates social presence for the receiver [...]. The researchers found that people prefer to use richer channels to be able to more efficiently and more effectively understand one another "(Dalkir, 2008, p. 93). Practically, it's important to consider not only differences between different technologies (such as telephone vs. ICT technologies or the Internet), but also the differences between Web 2.0 applications.

- Different type of contents: it's clear that a double set of contents discussed toward diabetes does exist. A public sphere of diabetes, regarding scientific advances and general information on diabetes is spread mainly throughout blogs. On the other side, it's possible to find a variety of contexts in which a private dimension of diabetes is discussed in a protect group of peers, such as in a dedicated forums or Facebook groups.
- Different type of actors: different actors have different aims and they use the Web 2.0 tools to reach their aim and to find useful knowledge. Our data confirm literature on the topic: patients and caregivers look for sharing knowledge (useful and practice) and support (Ancker et al., 2009). It's a new and relevant result to understand that diabetic patients look more for practical knowledge; instead their caregivers are more interested in emotional support. This result will help professional to better understand the different needs of all the actors involved in the care process.

This map allow us to move a step forward in the plethora of peer exchanges and knowledge processes toward the diabetes; in our opinion similar processes may happen toward other chronic conditions, even if it will be really important to verify the role of the disease in shaping knowledge processes.

Finally, we were able to detect those contexts that seem more able into favor interactions and support sharing between patients and caregivers. Indeed, interactions, discussions and sharing processes are supported mainly by group oriented contexts in which the model of "legitimation of knowledge" is horizontal (such as forums of

Facebook groups), where the actors of exchanges are patients and their caregivers and the exchange is focused on private and practical aspects of diabetes management.

Briefly concluding, thank to the brief knowledge processes review we understood that we are interested into the ideas proposed by the learning processes studies. Then by the results obtained by this study we were able to define which types of online contexts are able to support interactions and sharing between participants. In the next chapters we will deepen the study of these online contexts in order to understand how it may possible to develop knowledge sharing and construction processes.

CHAPTER 4

Identifying social and situational ingredients for "In a top shape" online contexts

4.1 Preliminary remarks

Study 1 of this dissertation detected those online contexts in which interactions and online learning knowledge processes (such as sharing, construction, building) seem to be possible 15. These contexts are framed by two main social features: they are group oriented and construction of knowledge is legitimated by peers. We were able to characterize them according to:

- Their technical features: they are all supported by forums and Facebook groups.
- The main actors of the exchanges and interactions: peers, in particular patients and their caregivers.
- The main contents: they deal with the private aspects of diabetes, such as management of the therapies or diet.

We "localized" them in the area called "interacting" (see *Figure 4.1*).

¹⁵ Literature define interactions the base for learning and online knowledge sharing, construction and building (Sing, & Khine, 2006). We don't mean that interactions and knowledge processes defined according to learning studies are the same, but the second ones happen only when people interact and discuss. According to this assumption this study will focus on the ability of online contexts to support interactions, as ground for knowledge sharing and construction processes.

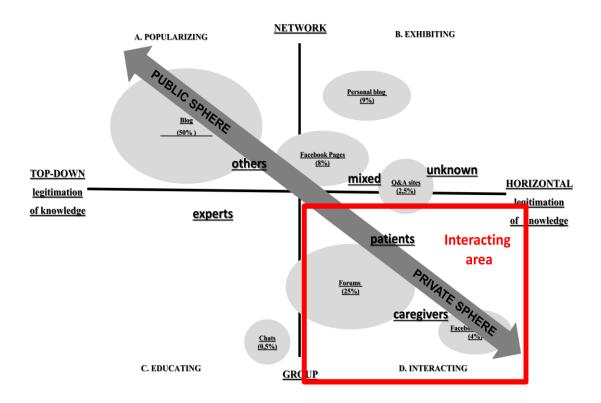


Figure 4.1- Interacting area (from study 1)

According to study 1, "interacting" area is the one in which we detected the main number of interactions and sharing processes. Anyway, not all the online contexts (characterized for Web 2.0 applications, actors and contents as we summarized above) show interactions. According to *Table 4.1*, in Study 1 we considered 48 online contexts that presented these characteristics, but only 65% of them presents interactions between participant after a first post. That means in 35% of the online contexts considered, someone posts a message (or more than 1 message) about diabetes but no one answers. So no interaction was created and consequently there wasn't any possibility for sharing and constructing knowledge.

		N. of online contexts presenting	
	Online	interactions after the	
	contexts	first post	
Forums	40	26	
Social Networks: groups	8	6	
TOTAL	48	32	

Table 4.1- Number of online contexts where interactions after the first post occur (frequencies)¹⁶

Starting form this evidence, the aim of this second phase of the research is to understand what are the situational, social and relational aspects that make interactions, and knowledge sharing, construction and building possible.

In our opinion, it depends on the ways in which people construct, use and give meaning to the online contexts.

Starting from literature about learning processes, we will detect theories and models that will help us in the understanding what types of situational, social and relational contexts can favor knowledge sharing and construction processes. Then we will apply them to the diabetes case, in order to detect what are the main features that characterize forums and Facebook groups analyzed and make them able to support (or not) interactions and knowledge sharing, construction and building processes in the diabetes field.

4.2 Learning and knowledge processes: what model?

In the previous chapter, we detected knowledge sharing, building, creation and construction labels (see *Table 3.1*) as the ones who describe the processes we are interested in and we stated that these concepts have their roots in educational and learning fields.

But what are the conditions that may favour these process?

We turn again to learning field in order to find some answer.

First of all it is necessary define what we mean using the word learning and why the considered processes can be considered as learning activities.

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¹⁶ Based on the first study dataset.

Literally to learn means: 1. to gain knowledge of a subject; 2. to find out information; 3. to change your behaviour (Longman Dictionary of Contemporary English, 2001).

Even if this clarification can seem obvious, this is exactly what patients do in their online peer interactions (and more in general, in their exchanges) with the aim to understand what the better behaviour to cope with their illness or health situation is. So we can state that patients and participants into online peer exchanges on health are learners looking toward a context that allow them to acquire knowledge acted to improve their care.

Learning is one of the most studied area of psychology and it has been studied according to many different paradigms: behaviourism, cognitivism, constructivism and connectionism (Trentin, 2010). Some of these position are outdated (e.g.: behaviourism) while the others coexist.

In order to untangle the complex panorama of the learning theories it is useful consider three main polarity:

- **objective** vs **constructionist** learning: the first position considers the learning as the storage and then re-use of knowledge already established; the second one propose learning as "an active process in which learners construct new ideas or concepts on the basis of their existing knowledge and experience" (Trentin, 2010, p. 27). This second perspective takes its roots in the Vygotsky's work (1978).
- Learning as an **individual activity** vs learning **takes place in a group setting**: according to the first position (used mainly in a cognitivist perspective) "knowledge is the result of mental processing generated by new stimuli" (BenbunanFich, & Arbaugh, 2006, p. 779). Each individual receives information from the external context and the learning process is the set of actions that he/she does in order to transform these information in useful knowledge and store it in his/her memory network. In this approach technology has the mere role to "provide the most effective stimuli to improve knowledge acquisition" (BenbunanFich, & Arbaugh, 2006, p. 779); instead the second one proposes the learning as a process of "participation and interaction" that "takes place among and through other people and artifacts as a relational activity, not an individual process of thought" (Brandi, & Elkjaer, 2011, p.28). This approach is strictly linked to the constructionist

perspective insomuch as a social constructivist approach to learning does exist; according to it "learning environments that encourage active participation, interaction and dialogue provide students with opportunities to engage in a process of knowledge construction as they try to create meaning from new experiences" (Pena-Shaff, 2004, p. 244).

• Learning is **susceptible to control and direction** vs learning **naturally evolves** (Shipton, & DeFilippi, 2011): this dimension opposes a learner that is more or less a passive subject that answer to different type of external stimulus, to an active person that acts learning as emergent and improved by each practice and experience of our life (Shipton, & DeFilippi, 2011).

Considering our starting point – the production and construction of knowledge in online peer exchanges – our approach toward learning and knowledge processes is **social constructivist.** We think that knowledge is something that can be created by people, through their interactions, sharing and negotiating their experiences and their practices. In the online literature, this branch of studies has its own label "Computer Supported Collaborative Learning (CSCL)": its aim is to create systems and tools to support the building of shared knowledge and knowledge negotiation (Sing, & Khine, 2006).

Now we have a framework useful to read our phenomenon, but we are not sure about its name: different models of knowledge and learning processes, in fact, are part of this huge paradigm. Moreover, we are looking for a theory/model that helps us to understand what is the context in which the learning processes happen.

To understand what is the term we need to adopt and what theories can guide our work ,it is important to briefly present the theoretical frameworks in which the different knowledge processes - building, construction, creation and sharing – are developed and studied.

In reality, literature proposed mix or just juxtaposition of these models to frame the same research work. Moreover the different labels of knowledge processes are used without considering their reference context (for example the term knowledge building is always used in the COP paradigm – e.g.: Markauskaite, & Sutherland, 2008).

Anyway, the most known and used models for CSCL are four. The first two models focus on the ways in which learning works, instead the other two established contexts and conditions that allow learning.

We will briefly present them, stating if they work or not for our purpose:

- **SECI** model: developed initially by Nonaka and Takeuchi (1995). Knowledge is created by individuals and groups in social contexts according to a specific flow that comprehends: Socialization of the knowledge, also tacit¹⁷, Externalization or explicit statement of knowledge; Combination of different information and position and creation of new knowledge; Internalization of this new knowledge (Hosseini, 2010). In this paradigm the label used is the knowledge creation. Even if this model is really clear and well defined, it doesn't refer directly to the group's knowledge processes, but it deals with an all-encompassing process that consider in big part individual learning.
- Activity Theory: developed by Engstrom (1999), starting from Vygotsky's theories. It's a triangular model (see *Figure 4.2*) that includes subject, object, and tool and shows the relationships between each item to mediate an interaction. This is a framework to guide the understanding of interactions and learning also in online environments (Baran, & Calgitay, 2010). As the SECI model, this theory doesn't focus on group knowledge construction and sharing processes but on a comprehensive model of learning that is too broad to study the processes we are interested to.

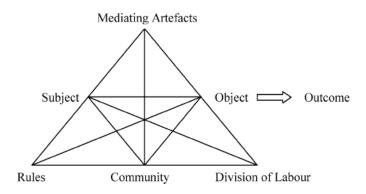


Figure 4.2 - The expanded mediational triangle (from van Aalst, & Hill, 2006)

• **knowledge building community**: developed by Scardamalia and Bereiter (2003). This kind of community was born in order to create an environment socially and

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¹⁷ See Chapter 5, paragraph 5.2.

technically developed to maximize the knowledge building possibilities trough activities, usually tasks given by a moderator or a teacher. According to Scardamalia and Bereiter (2006), knowledge building is based on these principles: 1. knowledge advancement as a community rather than individual achievement; 2. knowledge advancement as idea improvement rather than as progress toward true or warranted belief; 3. knowledge of in contrast to knowledge about; 4. discourse as collaborative problem solving rather than argumentation; 5. constructive use of authoritative information; 6. understanding as an emergent. Even if these principles are all applicable to the online peer exchanges, we think knowledge building framework can't really fit to our purposes. It states that knowledge building can happen within ad hoc built environments in which there are instructors that propose specific tasks on which build knowledge; this approach doesn't consider spontaneous exchanges and interactions, such as patients exchanges and interactions happening online as a learning environment.

• **situated learning and communities of practice:** developed by Lave and Wenger (1991). "To situate learning means to place thought and action in a specific place and time. To situate means to involve other learners, the environment, and the activities to create meaning. To situate means to locate in a particular setting the thinking and doing processes used by experts to accomplish knowledge and skill tasks" (Stein, 1998). In this paradigm communities of practice (COP) is the context in which people learn. COP "are an aggregate of people who come together around mutual engagement in an endeavor. Ways of doing things, ways of talking, beliefs, values, power relations – in short practices – emerge in the course of this mutual endeavor. As a social construct, a CofP is different from the traditional community, primarily because it is defined simultaneously by its membership and by the practice in which that membership engages" (Eckert, & McConnell-Ginet, 1992, p. 464).

This approach seems to fit really well to our purposes: in fact it focuses on the group dimension and try to define how people learn in naturally occurred social contexts. The labels used in this approach are knowledge sharing and knowledge construction.

The aim of the next paragraph will be to define online COP as the context in which knowledge sharing and construction processes happen, describing its features and showing the main branches of research.

4.3 Defining online community of practice (COP)

In the previous paragraph we established why the COP is the framework we chose and why we use the labels knowledge sharing and construction to define the processes we are interested into.

The aim of this paragraph is to define what we (and the literature) mean using this concept/label, if and how the role of the online environment can shape it and why it can well fit to online contexts in which interactions about diabetes happen.

4.3.1 What is a COP?

Firstly we want to briefly discuss what a community of practice is, as learning framework and learning context, and what its main important features are.

The first definition of COP is the following: "a community of practice is a set of relations among persons, activity, and world, over time and in relation with other tangential and overlapping communities of practice. A community of practice is an intrinsic condition for the existence of knowledge, not least because it provides the interpretive support necessary for making sense of its heritage" (Lave, & Wenger, 1991, p.98).

An easier definition is given again from Wenger - who can be considered the father of COP - ten years later: "groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis" (Wenger, McDermott, & Snyder, 2002, p 4).

To better define the concept we will propose the main characteristics of online COP. Keywords in the COP paradigm are:

• Community: "a community of practice is not just a Web site, a database, or a collection of best practices. It is a group of people who interact, learn together, build relationships, and in the process develop a sense of belonging and mutual commitment" (Wenger et al., 2002, p.34). As already established the construction of

knowledge is situated in a communitarian environment. This community is characterized by (Wenger, 1998): 1. joint enterprise: people negotiate a practical aim to pursue; 2. shared repertoire, namely a set of shared resources, knowledge, and culture that is a resource for the community; 3. mutual engagement: people are moved by a common aim and they are involved in activitities in which they mutually help others to solve their problem (Pan, & Leidner, 2003).

- Practice: "Each community develops its practice by sharing and developing the knowledge of practitioners in its domain. Elements of a practice include its repertoire of tools, frameworks, methods, and stories as well as activities related to learning and innovation" (Snyder & Weneger, 2010, p. 110). The focus of knowledge processes in COP is toward practical knowledge concerning activities in which participants to COP are considered as experts.
- Domain: "a community of practice focuses on a specific 'domain,' which defines its identity and what it cares about". (Snyder & Weneger, 2010, p. 110).

The participation to COP allows the construction of:

- Meaning: it is what has been produced by COP; people in COP through the sharing
 of knowledge experiences and practices are able to construct new meanings to their
 experiences;
- Identity: being part of these kind of processes determine not all meaning giving to external experiences but also to our own identity. The identity is a negotiated experience of ourselves (Wenger, 1998).

Another characteristic of COP is relevant in our perspective:

• COP are born form natural context: as we already said community of practice naturally occurs. It is possible to cultivate them but not to create them: "the community of practice draws its strength from the fact that it is informal, driven by the desire to share expertise, sets its own agenda and its own shape, and is sustained by the interest and passion of participants" (Davenport, 2001, p. 66).

Learning in the COP works according to two main processes: participation and reification.

The first one is the social experience to being part of the community. This is the moment in which people share knowledge.

The reification refers to the processes in which peopple give form to their understandings, experiences, practices by producing objects which express them. This moment is the moment of the knowledge construction and application.

4.3.2 Application of COP model to the online contexts

The use of "community of practice" has been linked to the online environment since its birth, in the middle of 90's. This field of study and application, thanks to the growing relevance of the Internet is subject to a continuous increase in the last 15 years (see *Figure 4.3*).

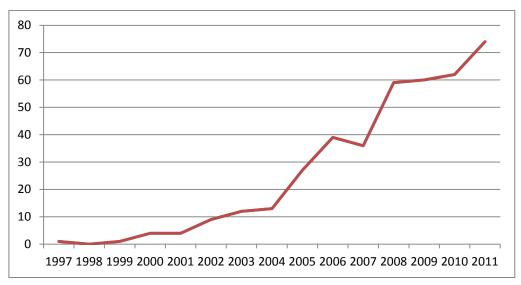


Figure 4.3- Number of paper about online + "communities of practice" per year 18

The study of online COP born from the idea that technology can be a tool to improve the wellbeing and the growing of COP (e.g.: Mojta, 2002). According to Wenger, White and Smith (2009), some "technologies have been invented because someone recognized a need in a community was not being addressed" (p. 18). According to this perspective COP is offline and uses some online or web tools just to improve its functioning. (e.g.: Cuthell, 2008)

Only in second time, the interest move towards online COP as independent from the offline (Rosenbaum, & Shachaf, 2010).

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¹⁸ As already said, the literature review has been based on the databases Scopus, Pubmed, Psychinfo and Google scholar. This graph has been developed using Scopus analytics tools. The year 2012 was not inserted in the graph because it's not already finished, but we cosider its articles in the review process.

Below we propose 2 main reflections on the use of this concept in the online framework.

Firstly, what are the features of an online COP?

Online COOP are based on interactions and discussions (Clarke, 2009). This is the channel that allows learning and knowledge sharing and construction processes (Zheng, & Spires, 2011).

It's clear that being in the online environment influences the COP in its basal components, such as collaboration, trust among members, and the sense of belonging, because the exchanges in online contexts can be harder (Dubè, Borihs, & Jacob, 2006). Some authors use the concept of "social presence" to legitimate the possibility of online COP, stating that it is "an important antecedent to collaboration and critical discourse because it facilitates achieving cognitive objectives by instigating, sustaining, and supporting critical thinking in a community of learners [...] students value social presence as a means to share ideas, to express views, and to collaborate" (Annand, 2011, p. 43).

Other authors (e.g.; Wasko, Teigland, & Faraj, 2009) use the term online network of practice to underline that the links between member online are "indirect rather than the direct links of a community of practice" (Cox, & Morris, 2004, paragraph 2) because, usually, members don't know each other.

Wenger et al. (2009) state that online group or communities can be considered COP if they respect the three fundamental dimension: domain, community and practice. This perspective is sustained also by the work of Murillo (2008) who looked for COP in the naturally web, using a grid developed by the main features of COP, and found that "communities of practice spontaneously emerge in the social areas of the Internet constitutes new support for Wenger's (1998) position that communities of practice are naturally occurring social structures" (paragraph Implications).

We agree with this perspective because we think that these dimension can be reached in online contexts. Anyway there is a new question: if the COP core features can (r)exist in online environment, are there other aspects that change? What are the main dimensions for online COP?

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¹⁹ Plainly, social presence refers to "the feeling of being present with another person at a remote location" (Allmendinger, 2010, p. 46).

An interesting answer is proposed by Dubè *et al.* (2006), and revised by Hara, Shachaf, and Stoerger (2009), who tried to categorize online COP in the context of organizational studies. Partly the provided categories are strictly linked to the organizational context, but some can be interesting to consider studying online COP (see *Figure 4.4*)

Dimension	Original typology (Dubé et al. [17]) (confined within an organizational context)	Modified typology (also includes open online CoPs)
Demographics	Orientation (operational–strategic) Lifespan (temporary–permanent) Age (old–young) Level of maturity (potential–transformation)	1. Orientation (operational-strategic) 2. Lifespan (discrete-continuous) 3. Age (young – established – old) 4. Level of maturity (potential – transformation + stability + disband)
Context ^a	1. Creation process (spontaneous—intentional) 2. Boundary crossing (low—high) 3. Environment (facilitating—obstructive) 4. Organizational slack (high—low) 5. Degree of institutionalized formalism (unrecognized—institutionalized) 6. Leadership (clearly assigned—continuously negotiated)	1. Creation process (bottom-up – top-down) 2. Boundary crossing (low-high) a. profession b. organization 3. Knowledge sharing culture ^a (low-high) 4. Organizational sponsorship ^a (yes-no) 5. Environment 6. Organizational slack (high-low) ^b 7. Degree of institutionalized formalism (unrecognized-institutionalized) ^b 8. Leadership (clearly assigned-continuously negotiated) a. active participants ^a b. founding members ^a c. moderator (+rotating) ^a
Membership characteristics	 Size (small-large) Geographic dispersion (low-high) Members' selection process (closed-open) Members' enrollment (voluntary-compulsory) Members' prior community experience (extensive-none) Membership stability (stable-fluid) Members' ICT literacy (high-low) Cultural diversity (homogeneous-heterogeneous) Topics' relevance to members (high-low) 	1. Size (small-large) 2. Geographic dispersion (low-high) 3. Members' selection process (closed-open) 4. Members' enrollment (voluntary-compulsory) 5. Members' prior community experience (extensive-none) 6. Membership stability (high-low) ^b 7. Members' ICT literacy (high-low) 8. Cultural diversity (homogeneous-heterogeneous) a. national ^a b. organizational ^a c. professional ^a 9. Topics' relevance to members (high-low)
Technological environment	Degree of reliance on ICT (low–high) ICT availability (high variety–low variety)	Degree of reliance on ICT (low-high + solely reliant on ICT) ICT variety (high-low)

Figure 4.4- Dimension for COP typologies (Hara et al., 2009)

These works established these variables as constituting different COP, anyway there is no evidence about how these main dimensions can differentiate online COP from other online of contexts and if they are able to distinguish between online COP more or less able into support knowledge sharing and construction processes.

The second reflection regards the topic coverage.

Classically, the study of online COP is developed in the organizational and learning field. In this perspective, the interest is mainly to consider a specific - and often ad hoc built - COP and understand its functioning, its peculiarities, its vantages or disadvantages in that specific context.

In the last years, instead, there is a growing movement to "cross the organizational boundaries" (Hara *et al.*, 2007). The idea is that the concept of COP can be applied to other online contexts that naturally exist in the web. According to Rosenbaum and Schahaf (2010) "one feature common to these communities is that they are digitally mediated and persistent settings within which people routinely interact, constituting and reconstituting their social worlds over time" (p. 1935). Considering this definition it is easy to affirm that, generally speaking, COP fits perfectly as a framework for online contexts we are considering.

Moreover specifically considering the interconnection between online COP and the health field (not considering literature about COP and online COP of health professionals, that is very rich – e.g.: Hara, & Hew, 2007) the link between COP and online contexts that support patients interactions it's just theorized (Roos, 2003; Stommel, & Koole, 2010).

We can affirm that the basic principles of community of practice can be theoretically and intuitively applied on the online contexts we labeled in the interacting area (see Study 1). Just intuitively, we can say that they own the basic features of COP because of their:

- 1. Orientation toward a group: people in these exchanges have a strong mutual engagement and they share a repertoire of knowledge towards the illness or the health question they are talking about.
- 2. Horizontal legitimating of knowledge: according to Wenger *et al.* (2009) "patients have to develop a practice of living with their disease. They can truly be called practitioners in the sense of sharing a practice" (p. 6). In this perspective they are, and are considered, as experts of their disease.

- 3. Content: they have a common aim, namely to better manage their or someone else health; moreover they referring to a pragmatic and problem solving dimension.
- 4. Actors: they are patient and caregivers that, as we said in point 2, can be considered as expert or professionals of their illness.

Starting from this literature review, we think that online COP seems to be a good paradigm on which ground the study of the social and situational features that shape online contexts able to support interactions and knowledge sharing and construction processes, but:

- The concept of online COP hasn't been applied to online exchanges about diabetes (and more in general chronic disease)
- Even if typologies of online COP have been developed in literature (Dubè et al., 2006; Hara et al., 2009), it's unclear what features really allow the life of online COP and the processes of knowledge sharing and construction that happen within them.

4.4 Aims

In the light of COP theories, the aim of Study 2 is to understand what dimensions make the online contexts detected in Study 1 able into support interactions and knowledge sharing and construction processes and the conditions that may foster or hinder interactions and knowledge sharing and construction processes. Starting from literature, we consider in particular, the social and situational aspects that framing and differentiating COP (Dubè *et al.*, 2006; Hara *et al.*, 2009) in order to understand how they shape the online context.

4.5 Method

4.5.1 Data collection

We monitored the Italian forums and Facebook groups **dealing with diabetes** for 1 year (October 2011- October 2012). We chose to focus only on those online contexts who had at list one section dedicated to diabetes and not just one thread or one post, without considering sites focused on other topics (such as cooking, fitness, alternative medicine)

that presented one discussion or post about diabetes. This choice is coherent with the COP concept: we chose those online contexts that have diabetes as domain.

The starting sample was composed by the forums and Facebook Groups dealing with diabetes detected by study 1. Then we searched for new ones in October 2011, February 2012 and October 2012, by using Google and Facebook search engines. In all, we monitored 20 online contexts: 4 forums and 16 Facebook groups. All forums were detected by the first study. Concerning with Facebook groups: 3 didn't exist when the first study run and 5 hadn't any post/discussion in the period considered.

We followed the forum and Facebook groups life by non participant observation. This tool is not invasive and it protects the speech naturalness in the online communities' space: "the unobtrusive approach to the research also protected the smooth running of the support forums. Announcing the researcher's presence would have disrupted the natural exchanges of postings that occur among forum users" (Gavin, Rodham, & Poyer, 2008, p. 326).

4.5.2 Data analysis

Firstly, we were interested into the ability of the online contexts to support interactions. So we monitored interactions in each context considering:

- a. The number of starting posts (namely, posts that introduce a topic or a discussion or a thread) in one month
- b. The number of discussions activated by a starting posts (namely, the number of starting posts that receive answers) in one moth
- c. The ratio between starting posts and activated discussions
- d. Comparing two periods of time (October 2011 and October 2012) in order to consider the trend.

Secondly, starting from the typologies of COP proposed by Dubè *et al.* (2006) and Hara *et al.* (2009), we developed an analysis grid.

The grid comprehends 5 main areas. Briefly, we explain the process of grid adaptation from literature.

- 1 Demographics: this area "refers to generic characteristics of online CoPs" (Hara et al., 2009, p. 742). Originally (Dubè et al, 2006) this area comprehended 4 item: orientation, lifespan, age, level of maturity. We didn't considered:
 - Lifespan: it opposites temporary COP to permanent COP defined as "an on-going mechanism for information sharing" (Dubè et al., 2006, p. 75). According to this definition, all the contexts we studied can be considered as permanent and this item is not able to differentiate context.
 - Level of maturity: it refers to groups that explicitly define themselves as COP. They have specific stages of development (Wenger *et al.*, 2002). In our case, it isn't possible to previously define stage of life of the considered contexts.

Instead, we considered orientation and age as follow:

- a. <u>Aim</u>: this item is an adaptation of the original item "orientation". Discussing the item "orientation", Dubè *et al.* (2006) stated that "*VCoPs may be created for different purposes; some have strategic implications while others are operational in nature*" (p. 75). Practically, we are not interested into the strategical or operational dichotomy, as it refers mainly to work contexts, but we consider the purposes that move the creation of a COP really important. So we analyzed if the online contexts have an aim and what it is.
- b. <u>Age</u>: we operazionalized this item by considering the year in which the online contexts (or their part regarding diabetes) was born.

Moreover, we added one item to this area:

- c. Online context focus: firstly, we considered if the online contexts were focused only on diabetes or if diabetes is just a section of the website. Moreover we detected if the online contexts referred to diabetes in general or to specific aspects of diabetes (e.g.: diabetes and insulin pumps).
- 2 Membership characteristics: the original items for this area were: Size, Geographic dispersion, Members' selection process, Members' enrollment, Members' prior community experience, Membership stability, Members' ICT literacy, Cultural diversity, Topics' relevance to members.

We didn't considered:

- Members' ICT literacy: it refers to "the number of members of online CoPs who are comfortable with ICTs" (Hara et al., 2009, p. 750). We weren't able by our observation of the online contexts to define the degree of ICT literacy of the members. Anyway, we considered all participants to interactions have a good ICT literacy because they spontaneously participate in online exchanges.
- Topics' relevance to members: "topic may be close to the daily work of its members or, on the opposite, be important for the or- ganization, but far away from the members' day-to-day preoccupations" (Dubè et al., 2006, p. 81). In our case, the relevance of the topic is high for all the participants as they have to daily face with diabetes.

We considered and operationalized:

- a. <u>Size</u>: we considered the number of the people enrolled for the online forums or Facebook groups.
- b. Geographic dispersion: connected "to the physical location of the participants" (Dubè et al., 2006, p. 78). We considered if participants where spread around all the Italy or if they were located in a specific area
- c. Members' selection process: "an open membership whereby anyone who has access to a computer and an Internet connection can become a member and participate [...] A VCoP may also choose to have a closed member- ship and to admit only people who meet a predetermined list of criteria" (Dubè et al., 2006, p. 78). We opposite open groups and closed groups. In the closed groups a web master or moderator accept or not people who want to enroll.
- d. <u>Members' enrollment</u>: the original item concerns the degree of compulsoriness of the enrollment²⁰. In our case, enrollment is voluntary. Anyway, we maintain this item and we considered the type of enrollment required to participate.

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²⁰ It's important to underline that literature we are considering is referred to work context where people may be obliged to enroll to a COP.

- e. Members' prior community experience: it "refers to whether members have a shared history as members of the same group in the past" (Hara et al., 2009, p. 749). We considered if participants referred to previous online context's discussions or activities.
- f. Membership stability: "a VCoP may have permanent members (i.e., a stable membership), but can also have changing membership, ranging from moderately stable to fluid" (Dubè et al., 2006, p. 79). Because the online contexts we considered are not linked to a specific organization, and they are characterized by spontaneous exchanges, there is a huge participants turn over (e.g.: people who just ask one question one time). Anyway we considered if the analyzed online contexts have a stable core group or not.
- g. <u>Cultural diversity</u>: originally this item considered cultural diversity at three level: national, organizational, and professional (Wenger *et al.*, 2002). None of them fits with our case, but we considered possible cultural diversity between:
 - i. Patients and caregivers: according to their role, they construct different experiences and probably knowledge about diabetes. So we considered if the online contexts were mainly participated by patients or caregivers (considering that the main part of the contexts analyzed present exchanges between both patients and caregivers)
 - ii. Type of diabetes: we considered if the online context is more focus on type 1 or type 2
- 3 Context: it focuses on the environments in which COP develops and operates (Hara et al., 2009). Hara et al. (2009) stated 8 main items: Creation process, Boundary crossing, Knowledge sharing culture, Organizational sponsorship, Degree of institutionalized formalism, and leadership. We didn't consider: Knowledge sharing culture, Environment, Organizational slack because, and Degree of institutionalized formalism. They directly refer to the organizations who own the online COP. In our case, the online contexts are not owned by any organization. Instead, we reformulate the other items and considered:

- a. <u>Affiliation</u> (born by the merge of Creation process and Organizational sponsorship): we considered if the online context was created by patients or caregivers or if it was supported by association, research centers, hospitals or other organizations.
- b. Boundary crossing: the original idea refers to the fact that online COP usually put together people of the same organization, but who make different jobs, crossing the boundaries of a specific work team. In our case, starting from data analysis, we referred to the boundaries of the online context itself and we consider if and how people crossed the boundaries referring and connecting other online contexts or their real life to the online context about diabetes.
- c. <u>Leadership and moderation:</u> we considered Hara *et al.* (2009) typology of leadership.

One type of leader includes the core members who are more active in the online forum than others [...] The second type of leader is the founding members who may not be as active online. [...] The third type of leader in online CoPs involves moderators whose roles vary from filtering messages to handling and resolving conflict (p. 748).

- 4 Technological environment: it "discusses the extent to which CoPs rely on ICTs and the ways in which different ICTs are employed by CoPs" (Hara et al., 2009, p.742) and it comprehends Degree of reliance on ICT, and ICT availability. Practically we reformulated them as:
 - a. Degree of reliance on offline: "One VCoP may use ICT 98% of the time and meet only once a year, while another VCoP may use ICT extensively but meet three to six times a year, and yet another may meet face-to-face every month" (Dubè et al., 2006, p. 81). In our case the contexts analyzed are almost totally supported by online technologies. Anyway, we detected if people who participated in the exchanges also met offline.
 - b. <u>Type of Web 2.0 application</u>: starting from study 1, we decided to consider forums and Facebook groups. We consider this dimension in

order to understand if these two different applications support different types of contexts.

5 Contents: analysis by clusterization of online contexts based on their contents supported by NVivo 10 (see next paragraph).

Final version of the grid is presented in *Appendix C*.

4.5.3 The softwares

Data storage and analysis was organized and supported by using NVivo 10. (see Chapter 2, paragraph 2.5).

Moreover, we supported the content analysis by using the cluster analysis tool offered by Nvivo; namely it is "an exploratory technique that you can use to visualize patterns in your project by grouping sources or nodes that share similar words, similar attribute values, or are coded similarly by nodes" (Nvivo). We used it to detect content similarities and differences between the analyzed online contexts.

4.6 Online contexts description

4.6.1 Good and bad online contexts

At the beginning of this chapter, we reported that not all forums and Facebook groups analyzed in study 1 were able to support interactions between participants.

By our monitor we are able to confirm that the considered online contexts, even if they share basic similar features (web 2.0 application, main actors and contents) present enormous differences in their ability to support and maintain interactions (see *Table 4.2*).

Table 4.2 shows the number of starting posts per month, the number of interactions that born from those starting posts per month (namely the number of starting posts that receive answers) and the ratio of the two in order to understand what is the ability of the contexts to support interactions. Moreover we compered two different time period in order to monitor changing in the ability of the online contexts to support interactions.

N.		Oct 2011			Oct 2012					
	n. starting posts	n. interactions	% of discus- sions	n. starting posts	n. interactions	% of discus- sions				
1	22	20	91	20	14	70				
2	6	3	50	It	doesn't exist mor	nore				
3	8	3	37,5	9	4	45				
4	No discussion	ons/posts in the cl	hosen period	No discussion	ons/posts in the cl	nosen period				
5	95	60	63	17	9	52				
6	120	97	80	492	69					
7	41	26	63	1	0	0				
8	13	8	62	9	6	67				
9	358	182	51	298	217	73				
10		It didn't exist		12	0	0				
11	37	0	0	82	10	12				
12	6	0	0	27	11	41				
13	238	83	35	9	3	34				
14	81	20	25	2	0	0				
15		It didn't exist		3	0	0				
16	138	46	33	17	3	18				
17	40	7	17,5	37	17	50				
18	12	7	58	90	15	17				
19	0	0	0	5	1	20				
20	2	0	0	It	doesn't exist mor	re				

Table 4.2- Interactions descriptions

In our opinion, starting from *Table 4.2* it is possible to define 5 types of online contexts, according to their ability to support interactions.

- 1. 6 & 9: they present more than 200 starting posts per month and 70 % of these starting posts present discussions (that means someone else has commented or answer to that first posts).
- 2. 1, 5, 8, 12, 13 have dramatically less starting posts than the previous ones, but around half of them are followed by discussions.

- 3. 10, 11, 16, 17, 18: they have starting posts at least as the previous ones, but very few interactions start around those starting post.
- 4. 3,4, 7, 14, 15,19: they present few or no starting posts and no interactions
- 5. 2, 20: they have been closed during our monitor activity.

Starting from this categorization, we classified the online contexts according to their "fitness" in supporting interactions and consequently knowledge sharing and construction processes (see *Table 4.3*).

Туре	In top	In a discrete manner	Need to keep more fit	Totally out of	Died
	shape			shape	
N. of the site in	6 &9	1, 5, 8, 12, 13	10, 11, 16, 17, 18	3,4, 7, 14,	2, 20
table 4.2				15,19	

Table 4.3 – Online contexts "fitness" level

In top shape: 6 & 9 are in a great shape, they support a lot of starting posts and the main part of them starts a discussion and the possibility to share and construct knowledge.

In a discrete manner: this five online contexts are not so able to carry first posts (or opening threads in the case of forums) but when someone posts something, discussion is often created. This is important because interactions allow the possibility to share and construct knowledge.

Need to keep more fit: in this category, we considered online contexts that present starting posts (sometimes more than the sites in the "in a discrete manner" category), but they show a low level of discussions. As we already underlined, interactions between participants to the online exchanges are necessary for the development of knowledge sharing and construction processes.

Totally out of shape & Died: even if these contexts have the same basic features in terms of Web 2.0 application, main actors and contents (see study 1), they are not able to support in teractions between participants.

Why do these online contexts differ so much?

What are the main dimensions that shape them?

What the "ingredients" for "In top shape" online contexts?

4.6.2 Description of dimensions analyzed

In order to understand these differences, we analyzed the online contexts according to the grid presented in the method section (paragraph 4.5).

The following table (*Table 4.4*) summarize the features of each online context analyzed per each area analyzed (Demographics; Membership characteristic; Context and Technological environment).

	Demographics						Мо	embership					Context		Technol environ	0
N.	Aim	born year	Focus	Size	Geo dispersion	Open vs Close group	Members' Enrollment	Reference to previous act.	Presence of a stable core group	patients vs	Cul. Div.1 Types of diabetes	Affiliation	Boundary crossing	Leadership	Reliance on offline	Type of Web 2.0 app.
1	No aim	2006	Diabetes section	N.A.	High	Open	Mandatory to write; reading is open to	Direct referring to people & references to previous discussions		Patients	Both 1 and 2	None	None	Active core members group	None	Forum
2	Share information about diabetes	2006	Diabetes	N.A.	High	Close	Mandatory to write; reading is open to	References to previous discussions	No	Patients	Mainly type 1	Patients' association	None	1 moderator to filter messages and manage exchanges	None	Forum
3	Be free to inform about diabetes no links with any association or organization	2008	Diabetes	2354	High	Close	Mandatory to write; reading is open to	References to previous discussions	No	Both patients and caregivers	Both 1 and 2	None	Connection to local events	1 moderator to filter messages and manage exchanges	None	Forum
4	No aim	2005	Diabetes	196	High	Open	Mandatory to write; reading is open to	None	No	Patients	Both 1 and 2	None	Connection to a newer Facebook group	1 moderator who posts topics	None	Forum
5	Chatting about diabetes without any connection to associations or organizations	2009	Diabetes	311	High	Close	Mandatory to read and write to	Direct referring to people & references to previous discussions		Patients	Type 1	None	None	Active members group	None	Facebook group

	Demo	ographi	cs				Me	embership					Context		Technol enviror	
N.	Aim	born year	Focus	Size	Geo dispersion	Open vs Close group	Members' Enrollment	Reference to previous act.	Presence of a stable core group	patients vs	Cul. Div.1 Types of diabetes	Affiliation	Boundary crossing	Leadership	Reliance on offline	Type of Web 2.0 app.
6	An help to face diabetes, by sharing and supporting	2009	Diabetes (caregivers point of view)	1187	Medium: mainly south Italy	Close	Mandatory to read and write to (only in 2012)	Direct referring to people & references to previous discussions and group activities	Yes	Caregivers	Mainly type 1	Patients' associations	Connection to people real life connection to other facebook groups	Active members group & 1 moderator to filter messages and manage exchanges	2/3 meetings per year (little local groups)	Facebook group
7	No aim	2010	Diabetes	92	High	Close	Mandatory to read and write to	None	Yes	Both patients and caregivers	Mainly type 1	None	None	1/2 members really active	None	Facebook group
8	Sharing experiences	2009	Diabetes type 1	64	High	Close	Mandatory to read and write to	References to previous discussions	No	Both patients and caregivers	Type 1	None	None	I moderator who posts and who filters messages and manages exchanges	None	Facebook group
9	To inform and share experiences about diabetes	2008	Diabetes	1988	High	Close	Mandatory to read and write to	Direct referring to people & references to previous discussions and group activities	Yes	Both patients and caregivers	Both 1 and 2	Patients associations and other online groups	Connection to people real life & connection to other facebook groups	Active members group & 1 moderator to filter messages and manage exchanges	1/2 meetings per year	Facebook group
10	to support parents of diabetic children	2012	Diabetes association	312	High	Open	Mandatory to write; reading is open to	None	Yes	Caregivers	Mainly type 1	Patients association	Connection to a real association and to other facebook groups	I moderator who posts information and manages exchanges	Connection to association events	Facebook group

	Demo	ographi	ics				М	embership					Context	Technological environment		
N	. Aim	born year	Focus	Size	Geo dispersion	Open vs Close group	Members' Enrollment	Reference to previous act.	Presence of a stable core group	patients vs	Cul. Div.1 Types of diabetes	Affiliation	Boundary crossing	Leadership	Reliance on offline	Type of Web 2.0 app.
1:	to inform about innovations in the care of diabetes	2009	Diabetes association	212	Low (local)	Open	Mandatory to write; reading is open to	References to group activities	No	Both patients and caregivers	Mainly type I	Patients' association	Connection to a real association and to other facebook groups	1 moderator who posts information and manages exchanges	Connection to association events	Facebook group
1:	To reciprocally support and help by sharing experiences	2011	Diabetes and insulin pump	818	High	Close	Mandatory to read and write to (in 2011 and 2012)	None	No	Both patients and caregivers	Type 1	None	Connection to otherher Facebook groups	1/2 member really active & 1 moderator who actives discussions and who filters messages and manages exchanges	None	Facebook group
13	To put in contact young people and diabetes	2010	Diabetes	414	High	Open	Mandatory to write; reading is open to	None	Yes	Both patients and caregivers	Mainly type 1	None	Connection to people real life	I moderator who actives discussions and who filters messages and manages exchanges	None	Facebook group
14	Diabetes and insulin (strongly attack to other types of therapies)	2011	Diabetes	178	High	Open	Mandatory to write; reading is open to	None	Yes	Mainly patients	Mainly type 1	None	Connection to other Facebook groups	1/2 member really active	None	Facebook group
15	5 No aim	2012	Diabetes (caregivers point of view)	29	High	Close	Mandatory to read and write to (only 2012)	None	No	Caregivers	Type 1	None	None	l moderator who actives discussions and who filters messages and manages exchanges	None	Facebook group

	Demo	graphi	ics				Me	embership					Context		Technol enviror	8
N.	Aim	born year	Focus	Size	Geo dispersion	Open vs Close group	Members' Enrollment	Reference to previous act.	Presence of a stable core group	patients vs	Cul. Div.1 Types of diabetes	Affiliation	Boundary crossing	Leadership	Reliance on offline	Type of Web 2.0 app.
16	To assemble people in order to have mutual support	2010	Diabetes	420	High	Open	Mandatory to write; reading is open to	None	Yes	Both patients and caregivers	Both 1 and 2	None	None	1/2 people who activate discussions	None	Facebook group
17	Create a group of diabetes people who meet to run together	2010	Diabetes + sport	197	Low (local)	Open	Mandatory to write; reading is open to	References to offline group activities	No	Patients	Both 1 and 2	Patients association	Connection to a real association	1 moderator who post information	Online supports offline meetings	Facebook group
18	Diabetes and cycling	2011	Diabetes + sport	82	Low (local)	Open	Mandatory to write; reading is open to	References to offline group activities	Yes	patients	Both 1 and 2	Patients association	Connection to a real association	An active member group who post information	Online supports offline meetings	Facebook group
19	State personal experience about his child diabetes	2010	Diabetes	34	High	Open	Mandatory to write; reading is open to	None	No	Both patients and caregivers	Type 1	None	None	1 moderator who post information	None	Facebook group
20	No aim	2010	Diabetes	20	High	Open	Mandatory to write; reading is open to	None	No	Both patients and caregivers	Mainly type 1	None	None	1 moderator who post information	None	Facebook group

*Table 4.4- Online contexts descriptive features*²¹

²¹Descriptive categories of analysis are described in paragraph 4.5. This table doesn't comprehend category "contents" that has been analyzed by cluster analysis and will be later integrated in the presentation of the results.

It is a schematic representation of the ethnographic notes produced during the analysis. It should be a baseline for the reader, in order to support the reading and the understanding of the next paragraphs.

4.7 Defining ingredients for online contexts fitness

Starting from our ethnographic analysis (and considering *Table 4.xxx* as our baseline), we present the dimensions/components that seem to be the main important into differentiate the analyzed online contexts. Some of them refer directly to the analysis categories (such as: aim or affiliation) and maintain the same label. Instead, others are new and born by theelaboration of some analysis categories.

At the end of the description of each component we will provide a little box called 'Tips for "In top shape" online context' helpful to evidence practical aspects of each dimension.

4.7.1 The aim

Six online contexts (n. 1, 4, 7, 15, 16, 20) don't state any aim. Four of them (4, 7, 15, 20) are in the categories "Totally out of shape" and "Died".

According to this statement, Aim seems to be a really important point into engage possible participants and members, making explicit why that online context exists. Aim can be considered as the "identity" of the online context.

In terms of contents, the aims of online contexts in categories "In top shape" (6 & 9) and "In a discrete manner" (1, 5, 8, 12, 13) are focused on different aspects:

- they offer a place in which people may help and support each other...
- ... by finding useful, trustworthy and update information, that it's often difficult to have by traditional centre and their website...
- ... and by sharing and comparing opinions and experiences of people that share the same conditions ...
- ... Without replace practitioners and health worker.

Practically, they state their role both into inform and support patients and caregivers. Examples of the aims of the two sites in the "in a top shape" category:

"Confrontarsi, attraverso consigli e scambi di esperienze...Supportarsi attraverso il sostegno verbale. Aiutarsi per migliorare l'approccio psicologico di chi affronta l'esordio e la gestione . Informarsi, per avere l'opportunita' di conoscere e capire , questi sono gli obbiettivi che questo gruppo propone, senza mai volersi sostiurire al consiglio dell'esperto" [To compair in a group, by suggestions and experiences exchange. To sustain by verbal support. To help each others in order to foster the psychological approach of people who face the beginning and the management (of diabetes) To inform in order to have the opportunity to know and understand, these are the aims that this group proposes, without take the practitioner place].

"XXX intende raccoglierne il legato per offrire al lettore un'informazione quanto più corretta e all'avanguardia su tutto ciò che riguarda il diabete. [...] Questo sito offrirà inoltre la possibilità di scambiare informazioni, supporto e conoscenza attraverso lo sviluppo di una comunità diabetica "on-line" [XXX wants to offer to the reader the most correct and updated as possible information about diabetes. Moreover, this site will offer the possibility to exchange information, support and knowledge by developing an online diabetes community].

Instead, online contexts categorized in "Need to keep more fit" focus on just one of this aspect; for example number 10 is focused only on social support ("sostenersi a vicenda rendendo meno difficile la condizione di vita dei nostri figli e delle nostre famiglie" [to reciprocally sustain in order to make the life conditions of our children and families less difficult]), instead number 11 is focused on the sharing of information about diabetes care ("informare delle innovazioni e delle ultime applicazioni per la cura e la gestione del diabete" [to inform about innovations and updated applicartions for care and management of diabetes]).

Just one context (n.19) in "out of shape" category proposes very personal aim ("Mio figlio è dovuto crescere in fretta anche se non voleva.... La sua infanzia è stata interrotta da Mr diabete... Adesso ogni giorno è li con la mano tremante che si inietta l'insulina...Ed io ogni volta che lo guardo con quel suo visino dolce e rassegnato ho una fitta nel mio cuore" [My son needed to quickly grow up, even if he didn't want. His childhood has been interrupted by Mr Diabetes... Now every day he injects insulin

using his trembling hand... And eveytime I see his sweet and resigned face I have a stitch inside in my hearth]). It's clear that people don't perceive that space as a space where sharing their experiences and aim.

Tips for "In top shape" contexts:

- To clearly state the aim of the online context
- To propose contexts in which participants can find both information and social & emotional support

4.7.2 The boundaries

This dimension is born from reflections on the "analysis categories": Geographical dispersion, Open vs Close group, Members' Enrollment, References to previous communities activities, Boundary crossing, and Type of Web 2.0 application.

Online contexts classified as "In top shape" (6 & 9) and "In a discrete manner" (1, 5, 8, 12, 13) are characterized by two dimensions apparently opposite: they are all closed s (except for n. 13), in which a moderator accepts who wants to enroll, that live in a network that offer the most possible connections to the external environment. In fact, they are all supported by social network platforms (group 1 is a forum inserted in a big network).

Trying to explain better, the closeness of the online context allows participants to feel it as a group, as a protect space in which talk about aspects of their private life (management of the diabetes and emotions connected to it) ("a noi è servito tanto condividere emozioni e vita di tutti i giorni con il gruppo" [it was very helpful to us sharing emotions and daily life with the group]). As we will see later, a moderator tries to guarantee that the other participants are all people involved by diabetes. Moreover in close groups, enrollment is mandatory to read and to write to. That means everyone, readers and writes, has the possibility to see others profiles or information: having information about the other participants, it's fundamental in order to legitimate what the others post. Indicators on other participants identity really considered are: the presence of pictures ("Quest'anno finalmente risento lo spirito Natalizio si vede dalla foto del profilo..."[Finally, this year I feel Christmas mood as it's possible to notice by my picture...]) and the possibility to see the profile of each participant containing personal

information, such as gender, age ("come potete vedere non sono più una bambina" [as you can seen, I'm not a child anymore]), but also type of diabetes or information about the use of the forums ("xxx- utent esparto- numero di messaggi postati: 1348" [xxx- expert user-n. of messages: 1348]).

An interesting example is connected to one of the "In top shape" context (6) who moved from open group (that means people have to enroll in order to write, but everyone is free to read the posts of the group) to a close group (enrollment is necessary also for the reading); the moderator says about it: "Finalmente sono risucita a chiudere questo gruppo!! Spero che serva a fare sentire tutti meno esposti e più rilassati @" [Finally I could made this group closed!! I hope it will help people to feel less exposed and more relaxed@]. More than 100 hundred participants like this post and all the 23 people (exclusive of 1) answered to that post agreeing with it ("Ma sinceramente mi dava un po fastidio che tutti i miei contatti potessero leggere cose intime che potrei condividere con voi, perchè anche se non vi conosco personalmente, sono sicura che mi potete capire meglio di chiunque altro" [Onestly I was a bit annoyed by the fact that all my contacts were able to read intimate stuff I could share with you, because, even if I don't know you personally, I'm sure you can understand me better than anyone else]). The number of starting post and discussions is quadrupled after the group became closed (see: number of starting posts and discussions in October 2011 and October 2012).

Moreover, the feeling to participate in a close and selected group of people is given by the referring to some people, discussions or activities of the group. Indeed "In top shape" (6 & 9) contexts present posts directly referring to other members of the group ("Cara XXX ti do ragione" [Dear XXX, I agree with you), also calling them "friend" ("e' vero come dice la mia amica XXX" [it is as my friend XXX- name of one of the Facebook group participants- said]), to previous discussions ("come diceva XXX" [as XXX said]) and to activities (online and offline) proposed by the Facebook groups ("15 dicembre ci incontreremo tutti a Milano per lo scambio degli auguri di Natale" [December 15th, we'll meet all together in Milan for the Christmas Greetings]). The online contexts classified as "In a discrete manner" (1, 5, 8, 12, 13) and the majority of the ones in "need to keep fit (11, 17, 18) at least refer to previous discussions or activities. "Totally out of shape" and "Died" online contexts don't refer to any discussions or activities, showing a lack of shared "experiences".

On the other side, the site or group life and its being prolific depends on its **capacity to be connected to the other reference networks or groups** of the participants. In particular:

- 1. Facebook, and more in general big platforms or social networks, allows the connection with people's "real" life: participants and members of Facebook groups (that usually support more exchanges than forums), exist in a big social network where participants are not connected only to the group on diabetes but to people belonging to their offline life and to other groups they are involved in. Participants don't have to "go" to diabetes online contexts (as they do when they participate in a forum), but the Facebook group is "where they live". The only forum (n. 1) we put in the "In a discrete manner" category is a big platform where women (it is dedicated to women) can discuss about many topics (health, children, but also fashion) in forums; diabetes forum is just one of the health section, but in the same website they can participate into exchanges about many other topics. In fact, people use Facebook not only to exchange about diabetes but they create their profile, meet their friends, and participate to different interest groups as they decide to participate to a group focused on the diabetes. Practically, Facebook groups are where people use to be and people is often just exposed to the group posts (by notifications) ("Ciao Rosanna, sai perchè non riesco a ricevere sul mio profilo i vostri post?" [Hi XXX, do you know why I can't receive your post on my profile?]), instead people have to intentionally visit forums about diabetes. According to a technical perspective Facebook (and also the platform that support forum 1) proposes applications for devices different from the traditional computer, such as Smartphone and tablet, making the connection to the group easier (see *Figure 4.5*).
- 2. Connection to the diabetic community: the use of Facebook allows people to be part of more than one group about diabetes and that create a sort of community of patients that use some (the ones in the "in top of shape" and "in a discrete manner" categories) of the Facebook groups frequently, (for Christmas 2012, they decided to organize an event, called "A love Christmas", where people of three different groups 6, 9 and 13 could meet). Practically, the same people create discussions in different Facebook groups and they cite conversations or activities proposed in other groups ("è successo anche in XXX" ["it happen also in XXX"], or "Ti ricordi quell"

post, nell'altro gruppo XXX" [Do you remember that post on the group XXX?]). Instead it is possible to find the same message posted on different online contexts in order to receive more answers and suggestions. Practically, the regular frequenters use different Facebook groups as different tools of a big community, in order to maximize the help that they can have.



Figure 4.5- Facebook application fro Blackberry

A last reflection on this topic deals with geographic boundaries. In fact, even the main part of the contexts are national and this is a value for people, participants often look for people that live in the same geographic area because they feel to have more in common (same hospital or diabetic centre, same laws, but also same culture) ("C'è qualcuno di Roma?" [Is there someone from Rome?]; "Vi scrivo per sapere se c'è qualcuno del Piemonte e per capire se il problema che stiamo incontrando qui è diffuso: ieri in farmacia mi hanno negato il rifornimento di aghi, strisce reattive e pungidito in quanto la REgione non ha più pagato le farmacie??????" [I write to find someone form Piemonte in order to know if the problem we are facing here is spread: yesterday in the pharmacy, they denied the needles and other glycemic tools furniture because the region didn't pay the pharmacies????]). Sometimes it happens that participant of Facebook group met after they known each other online ("è stato emozionante partecipare e conoscere tante amiche "dal vivo"!!" [it was exciting to participate and meer so many friends in reality!!]). This is easier if the online contexts don't have high geographical dispersion (such as n. 6)

Tips for "In top shape" contexts:

- Context needs to be closed and selected in order to perceived as a safe and protect space...
- ... But connected to people real life...
- And to a whole and biggest diabetic community (that can be spread in different online contexts)

4.7.3 The affiliation

This dimension is born from reflections on the "analysis categories": Affiliation, Boundary crossing, and Reliance on offline.

Seven online contexts declare their affiliation to patients associations.

The affiliation define two types of online contexts profile:

- Context 6 & 9, classified as "In top shape", refer to association as authority who can guarantees for their work. Morevoer, referring to patients associations or medical centres is perceived as an indication to have some in common ("x le mamme in cura al I policlinico di Napoli: sapete se sono arrivate le strisce x la glicata o ci tocca il prelievo venoso???" [for mums that are follone by I policlinico of Neaples: do you know if they have glycosilated hemoglobin sticks or we need the draw blood?]). Some people clearly state to be member of some association and they discuss about their association and share its events and activities ("Associazione diabetici XXX Onlus- Oggi si parla di: A proposito di carboidrati con xxx- Siete tutti invitati" [Onlus XXX Diabetes Association- Today we will talk about charboydrates with the participartion of XXX- All of you are invited]). Moreover n. 9 is affiliated to other websites that provide information about diabetes and it is born by previous forums ("questo forum e' raramente frequentato ormai, perche' siamo su facebook" [this forum is rarely attended because we are on Facebook]). This is really a good point for it, because it can receive the inheritance of those websites and forums in terms of trustworthiness. Moreover, it's remarkable the ability of its moderators to change toward a tool that facilitates more and more exchanges.
- N. 10, 11, 17, 18, classified as "Need to keep more fit", have stronger connections with real associations. It's possible to say, in particular for n. 17 and 18, that they are an online tool of an offline community. Practically, they present few discussion because they are used as memories, experiences and knowledge storage by member of a group that meet, exchange and probably share knowledge offline ("*Ieri sera ci siamo divertiti,una bella serata! giovedi ci troviamo per una corsa in compagnia ciao*" [yesterday evening we have fun,, a great night! On Thursday we will meet for run together]).

Contexts 2 and 5 clearly to not have any connections with specific associations or institutions. For them, this is guarantee of freedom in information ("Uno spazio per chi vuole semplicemente chiaccherare sul tema, assolutamente indipendente rispetto ad associazioni e/o istituzioni" [A space directes to the ones who want just chatting on the topic, totally free from associations and istitutions]).

In all the online contexts, every type of connection (and sponsorship) to drugs producers or sponsor is perceived as a menace able to compromise the possibility of the context to carry exchanges (see also paragraph xxx of this chapter). It destroys the site trustworthiness. (1: "questa pubblicità è davvero pericolosa..." 2: "per favore, spammala" [1: this advertisement is really dangerous... 2: please, spam it]; "qui cominciano as esserci un po' troppi spam ©" [here we have too much spam ©]).

Tips for "In top shape context":

- Affiliation to patients associations may guarantee for the online contexts and it is a shared element between participants
- Connections with pharmaceutical organizations and drug producers are perceived as dangerous by participants
- If the focus is on the offline group (patient association), online context is just a repository for the offline group

4.7.4 The immediacy in the answer

This dimension is born by: Interactions description, Leadership, Types of Web 2.0 application, Presence of a stable core group, and in part it's data driven.

Immediacy in the answers entails the richness of the interactions, as people feel the possibility to receive answer when they need it. In this way, the exchange is able to supply the time limits of offline relationships (with practitioners or peers).

This dimension is really connected to the type of Web 2.0 application – forum or Facebook group. In fact, Facebook groups due to the their characteristics, such as the notification, possibility to download Facebook App on different devices and the proximity to other online activities of participants, allow **immediacy** in the exchanges and interactions. In forums, a first post receives answer after 1 or 2 days, instead

interactions in Facebook groups happen in two/three hours (see *Figure 4.6*). Just very rich discussions may continue for more than a day. In Facebook groups 6 ("In top shape"), some participant sfeel sorry to not participate to the exchange activity for one day ("purtroppo domani sarò fuori Milano e non riuscirò avedere cosa postereste, spero di riuscire a connettermi subito domani sera" [unfortunately tomorro I wil be outside Milanand I will not be able to check your posts, I hope to be able to connect right tomorrow evening]).



Figure 4.6– Differences in answer time between Facebook groups and forums

It's important to underline that not only technical features allow immediacy in the answer; indeed some Facebook groups haven't any interaction. It's necessary the presence of a pivotal group/person that maintains interactions alive, by posting new topics and answering to the others posts.

All "In top shape" and "In a discrete manner" online contexts have a stable core group (1, 5, 6, 9, 13) or at least 1 or 2 active moderators or participants (5, 8). Starting posts can be posted by many participants, but the development of the discussions and interactions is favored by the presence of "habitués". ("XXX.... Ci siete??? Se ci siete battete un colpo!!!! Il forum è deserto....!!" [XXX- directly using some participants nicknames- Are you here?? If you are here, knock at the door²²!!! The forum is abandoned])

-

²²²²This is an Italian way to say, in this case it can mean: please answer.

Finally, some participants express the tendency to write in online contexts where they read a lot of interactions ("siete in tanti a scrivere in questo gruppo, quindi credo che qualcuno sarà capace di rispondermi" [there is many people that write in this group, I think someone will be able to answer to me]).

Tips for "In top shape contexts":

- Immediacy in the answer is central for an online contexts as it supplies limits of offline relationships
- It depends on the web 2.0 application: Facebook group facilitates it
- But it is also provided by a core group of people who strongly participates in the exchanges

4.7.5. The moderation

The moderation is born by: Leadership and Presence of a core group.

Starting from the analysis of the online context, we were able to detect three types of moderation:

- The "puller": it is a little group (usually not just one person) that proposes discussion and that answers to others' post. This group can be considered as a puller able to activate discussion. As said in the previous paragraph this is the activity that the stable core group (or in case 5 and 8 couple or single person) does. It's important to notice that the puller/s opinions and experiences are not different from others ones. In fact, when the puller is perceived as more expert than the others, the dynamic is the same that happen with a practitioner or traditional expert (see Study 1), people don't share knowledge but look for his/her answer (this kind of relationship happen in forums 2 and 3) ("Cara XXX, vorrei sapere una tua opinione sulle mie frequenti ipoglicemie" [Dear XXX, I want to know your opinion about my frequent hypoglycemias]);
- The "facilitator": it is usually someone that helps others with practical and technical features and receives new ones. This moderation is often taken the person who creates the group. ("grazie XXX per gestire questo gruppo, sei davvero importante per tutti noi" [Thank you XXX to manage this group, you are so important for all of us]). In the analysis grid we refer to someone who managed the exchanges. (present

- for: 2,3,6,8,9,10,11,12,13,15). According to our analysis, to have a point of reference is important for participants who have some troubles. Indeed the groups in which no facilitator is present (3, 4, 7,14, 15, 19,20) stay in the "Totally out of shape" and "Died" categories (except for number 1, 5);
- The "controller": because of the importance of a safe setting (see section 4.7.2 about boundaries), the moderator can assume the role of the protector of the online contexts, removing spam and trolls ("Quello che ha per foto del profilo la Madonna con Giuseppe e il bambino e per copertina la rana a pancia all'aria chiede di nuovo di entrare nel gruppo: e non posso neanche inviargli un messaggio per chiedergli "chi sei?" mah!" [the one that in his profile has the picture showing Virgin Mary with Saint Jospeh and the bay and the background of is profile is a turned up frog, he asks again to enter in the group: and I even can't send him a message to ask: "who are you?"...]). This role is really important, because, as we already said, advertising and sponsorship of drugs and treatments really kill group life. Again, in online contexts classified as "In top shape" and "In a discrete manner" (except for 1 and 5) the creator/moderator of the Facebook group assumes this role.

It's important to notice that the "In top shape" online contexts present all the three types of moderation, even if they are provided by different actors (the first by the stable core group and the other two by the creator/moderator).

Tips for "In top shape" contexts

- 3 types of moderation favor the interactions:
 - The "puller": a group that stably participates to the group interactions, by posting topics and answering questions
 - The "facilitator": that helps others to solve practical and technical questions
 - The "controller": that check the group participants and exchanges, deleting spam and trolls

4.7.6 Cultural diversity

a. Patients versus caregivers

Participants in the online contexts are both patients and caregivers. In half of the online contexts, we can find both patients and caregivers (n. 3, 7, 8, 9, 11, 12, 13, 16, 19, 20), instead in 7 contexts the participants are mainly patients (1, 2, 4, 5, 14, 17, 18) and in three contexts mainly caregivers (6, 10, 15). In all the last three it is clear stated in the name or in the aim that they are specifically direct to caregivers. Another interesting reflection is that in "In top shape" and "In a discrete manner" categories creators and moderators of the online contexts are caregivers (except for n. 1, that has not a moderator, and 5). In particular a strong interest to involve in social activities and helping others is more evident in caregivers ("sono contenta che la vicinanza di noi mamme ti possa essere d'aiuto ...sarà un periodo duro ma poi vedrai tornerà il sereno <3" [I'm happy that the affinity of us, mums, can help you... it will be an hard period but the good and the positive will return]). This may depend by the fact that the main part of caregivers are parents who wants to help other children, but it's evident that social, support and associative components of the illness are really important for caregivers ("una bella iniziativa di una mamma della mia associazione che ha voluto condivedere con tutti i suoi contatti una riflessione" [this is a beautiful initiative of a mum from my association who shared a reflection with all her contacts]). Instead patients, that probably feel the illness already pervading their life, are less interested to the social and association life, but participate to exchanges to solve diabetes management problem. This analysis agrees with we already found in Study 1.

For example, one of the "In top shape" context (n. 9) is managed by the sister of a diabetic man; the same woman participates into many other groups and associations and manages a website about diabetes. Instead two of the groups managed by patients are referring to diabetes connected to running and biking (17,18) and they are aimed to facilitate life of groups that meet online not mainly for diabetes, but to do sports together ("Ho mail di gambe ma il morale a mille e dopo Punta Veleno oltre allo

Zoncolan che faro' proporrei la salita di Bocca di Forca che ne dite?" [I have leg ache, but my mood is great after Punta Veleno. Other than Zoncolan tha I will do, I will propose Bocca di Forca climb, what do you think?]).

b. Type of diabetes

The main part of participants in all online contexts is affected by diabetes type 1. No online context refers explicitly to diabetes 2, instead five online contexts (n. 5, 8, 12, 15, 19) are focused only on diabetes 1; and other eight (n. 2, 6, 7, 10, 11, 13, 14, 20) present mainly issues connected to diabetes 1 and their participants are affected by diabetes type 1. Even if we can't say that the type of diabetes of the participants affects the ability of the context to support interactions and knowledge sharing and construction processes, we need to reflect on two main aspects:

- Age: diabetes 2 people are usually (but not always) old and so probably they are
 not Internet confident. Anyway, few caregivers of these patients participate to
 the exchanges and they are probably not so old;
- Involvement: diabetes 1 is a pathology more complex to manage and more pervasive that affected patients since the childhood; for this reason diabetes type 1 people (and their caregivers) probably need more help and support ("il tipo 2 ha meno necessita di strisce insulina etc, la cura del tipo 2 non ha nulla a che vedere con la cura per il tipo 1!" [type 2 has less necessity of sticks, insulin, etc, the type 2 cure hasn't anything to do with type 1 cure]) and they are more involved in their care management.

We want to add a more reflection about the cultural diversity of the participants.

c. Adherence/compliance

The patients that involve in the interactions seem to be really adherent to their therapies. Obviously, they have problems, sometimes their monitoring is not good, ("mi aspetto un bel 9... visto il macello delle glicemie dell'ultimo mese.... tra ciclo, influenza e stress per l'inizio della scuola abbiamo dato il meglio per rompere l'incantesimo delle belle

glicemie estive!!" [I think I will have 9... considering the mess of glicemic indexes in the last month... period, flu, stress... at the beginning of the school, we did our best in order to breack the magic of the summer glycemic indexes]) and other times they share to eat something wrong or to forget the therapies, but they are seriously involved into their care and into find solution to their problems. Moreover it's obvious that participants trust other patients that they believe able to manage their diabetes ("GrazieXXX... Info azzeccatissima Graziegraziegrazie!" [Thank you XXX...very spot-on ansie...thank you thank you thank you]).

If someone says he/she doesn't manage his/her diabetes, it seems more an outburst (it's important to underline that some personal blogs analyzed in Study 1 were written by not adherent patients just to provoke) ("ed ora mentre vado a dormire tutto ciò mi viene in mente e mi sento impotente perchè vorrei migliorare ma non riesco a trovare una strada, la strada adatta a me e mi sento inferiore agli altri" [and now I go to sleep and I can only think that I feel powerless because I want to improve myself but I can't find the way, my way and I feel less than the others]). This topic is important because, even if Internet may reach everyone, it can only reach who wants to be found.

Tips for "In top shape" online contexts

- Patients and caregivers are mainly concerned toward different aspects of their diabetes management
- Online contexts can reach only people who want to be reached

4.7.7 The time framework

It is born by: Born year and Type of Web 2.0 application.

All the online contexts that we analyzed are relatively young: the older forum started in 2005 (4) and the other three between 2006 and 2008 (1, 2, 3); first Facebook group was born in 2008. There are not big differences in starting time between forums and Facebook groups.

Anyway, we will propose two considerations.

Firstly, a consideration about the oldest online contexts: they are forums and they are dying. This is not because they are too old, but because their culture is becoming old. And it's evident by two main point of view:

- The application they use: they are supported by old tools and old environments. As we already said, Facebook groups are able to better connect to people real life. Anyway, this is not only connected to their technical features, in fact forum 1 is constructed on a platform that has an app that allow to access to it by iphone and ipad. Or Facebook group 9 born from the migration of a group of people who used to meet on a forum and a chat and then moved to the Facebook group. Others just weren't able to change according to the technical development
- The language they use (see also paragraph 4.7.9): for example forum 4 refers to the user profile, by using use the term "avatar". This term, according to the evolution of Web has totally another meaning (see, for example, 2nd Life), instead the "avatar" in a forum, today is called profile.

That means forums are becoming old not only for their technical features, but because they aren't able to change.

Secondly, a consideration about the youngest. The online contexts classified as "In top shape" and "In a discrete manner" were at least 1 years old (except for 12) when we begun to monitored them Moreover the two "In top shape" (6 & 9) are two of the oldest, born respectively in 2009 and 2008. This probably means that people need time before starting to discuss, because they have to know the group and the people who manage and live in it and we aready stated to create a safe place.

This is for example confirmed by the big growth that n. 12 had from 2011 to 2012 in terms of first posts and exchanges.

Tips for "In top shape" online contexts

- The online context need time to be perceived by people as protect space in which interact
- It's necessary to be updated about technological changes and improvements

4.7.8 The size

We considered the size of the online contexts as the amount of enrolled people to each context. It's possible to notice that online contexts who present high number of participants, show more posts than the ones that have few participants; for example, "In top shape" online contexts (6 & 9) are the two most frequented Facebook groups and they have more than thousand people (n. 9 about to two thousands). Instead 4 of 7 classified as "Totally out of shape" or "Died" (7, 15, 19, 20) have less than one hundred participants (15, 19 and 20 less than 50). At first sight, it seems quite obvious. In reality, as we already said, the ability to create interactions and discussions is mainly based on a stable core group (the "puller") that comprehends few people. Anyway an active group attracts a lot of people. Many of them will be just lurkers²³ and many others will just post one message or two regarding a specific problem they have, but they will do it in a context in which they perceive there is someone else who will answer.

Tips for "In top shape" online contexts

- Having many participants can increase the number of interaction...
- ... but the interaction in the online contexts is mainly given by the "puller" group

4.7.9 Contents

In the previous presentation of the result we focused on the social and technical features that characterize the online contexts (starting from data in *Table 4.5*).

Our study methodology planed also an explorative analysis of the content, in order to understand if online contexts differing for social and technical features concern with different topics and contents (see paragraph 4.5)

Starting from Nvivo cluster analysis, we categorized the online contexts according to their contents²⁴ (*Figure 4.7*).

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²³ Lurker cab be generally defined as someone who reads the contents posted in an online context, but who doesn't participate. For a clear definition see Mo & Coulson (2010).

²⁴ Because of the too little amount of content (and obviously interactions), it wasn't possible to categorize n. 20

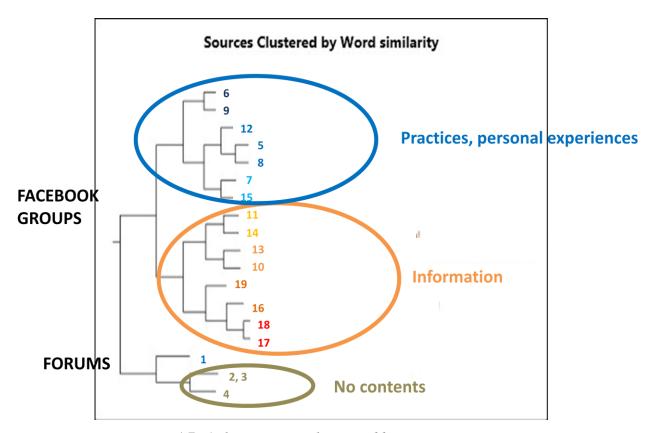


Figure 4.7- Online contexts clusterized by contents

A first ramification divides forums and Facebook groups because of the different technical language of the application (e.g.: Facebook uses word such as like, share or post, instead forums use "write a message", or quote, or avatar). Moreover, three of the four forums (2, 3 and 4) don't support many posts or exchanges, so they are "empty" of contents. The only good working forum is colored as a cluster of Facebook groups, because it can be assimilated to them.

Then a second ramification divides Facebook Groups: one first cluster is referred to those Facebook groups dealing with practices and personal experiences of participants; a second one is more focused on the sharing of information.

In the first cluster, participants share their life with diabetes sharing and discussing problems, practices, procedures, but also joy and difficulties. Even if, this group is divided into three more clusters they are quite similar, differing because:

• 6, 9 ("in top shape"): they deal diabetes 360 ("questa è una malattia che si vive nel quotiano ed intacca ogni aspetto della tua vita: lavorativo, sociale, familiare,

sessuale, hobbies e divertimento... tutto" [this illness impacts to daily life and it impairs every aspect of your life: work, social life, family, sexual life, hobbies and fun... everything]), not only considering cure and therapies but also all the other aspects of life that may be affected by diabetes: diabetes at school ("a scuola delego le maestre ma sanno che al minimo dubbio ho sempre il cell acceso" [at school I delegate to teachers, but they know that I always have my cellphone off for every dubt]), legal aspects connected to diabetes ("Permessi lavorativi Legge 104/1992" [Work licenze according to the law 104/1992]), social identity of diabetic people, stigma ("XXX sei stato chiamato in brutto modo (diabetico di merda)" SI MAMMA" [XXX have you been called in abad way? (fucking diabetic one) yes mum]), sexual life, psychological wellbeing ("certamente, in questo caso è indispensabile lo psicologo, sarà di certo un momento transitorio, un bacione e in bocca al lupo, fagli conoscere altri ragazzini diabetici in modo che si confronti con loro" [sure in this case a psychologist is necessary, i twill be temporary, good luck, try to present him other diabetic children so he can compair with them]);

- 12, 5, 8 (part of "In a discrete manner"): they are focused only on type 1 diabetes ("Sono contenta di potermi confrontare con altre persone con il mio problema, ho 17 anni e sono diabetica da quando ne avevo 12" [I'm happy I can compair with other peopple that have the same problem I have, I'm 17 and I'm diabetic since I was 12]);
- 7, 15 (part of "Totally out of shape") are focused on practical aspects of diabetes cure and therapies ("Ragazzi qualcuno ha il microinfusore Animas?Non riesco a scaricare i dati sul pc (in realtà ho problemi col cavo usb).Qualcuno mi può aiutare?" [Does anybody have Animas insulin pump? I'm not able to download data on my pc (actually I have some problems with the USB connection) Does anyone help me?])

Instead, the second cluster is more focused on the sharing and discussing of information towards diabetes. More in depth:

• 11,14 are focused on the associative aspects towards diabetes ("Il 13 e 14 di ottobre si è tenuta a Bologna la II Conferenza Nazionale delle Associazioni di Volontariato, due giorni nei quali le associazioni dei pazienti diabetici hanno potuto prendere la

parola per presentare le proprie realtà, esporre idee, sottolineare problemi, proporre le loro soluzioni." [The second national conference of voluntary work association was held October 13th and 14th in Bologna, there were tow days in which diabetic patients associations could present their realities, propose new ideas, underline problems ans propose their solutions])

- 13,10 are focused on the books, article and other scientific news about diabetes ("Il libro in uscita scritto da una nostra "collega" vi invito a regalarvelo per Natale!" [The book written by one our "collegue", I invite you to give it as Christmas present])
- 19,16 are focused on the sharing of information about practical management of diabetes (e.g.: they propose websites that allows carbohydrates count)
- 18,17 support the life of groups existing online ("grazie a chi ha partecipato ieri in associazione" [Thank you to the ones that yesterday evening attended the meeting at the association]).

Practically, the contexts that deal with the personal experiences of diabetes (except for 7 and 15 that don't have other necessary elements to foster interaction, such as the presence of moderator or the number of participants) are the ones in better shape. Instead the ones in the second cluster are probably more similar to Facebook pages (see Study 1), even if here people share information with a specific group.

4.8 A taxonomy

According to the presented elements it's possible to create a taxonomy of the analyzed online contexts (*Table 4.5*).

	In top shape	In a discrete manner	Need to keep feet	Out of shape/died
Status	Many starting posts Many % of answers/discussions	Few starting posts Many % of answers/discussions	Many starting posts -Few % of answers/discussions	Few starting posts NO % of answers/discussions
Aim	Aim: clearly stated - sharing and compare with other - trustable info - in a safe place	Aim: clearly stated - sharing and compare with other - 4 of 5 focused only on types 1	Aim: clearly stated - facilitating people encounter - usually (exclusive 16) people of already existing offline groups	Aim: not really clear - 4 of 8 have no aim -1 aim related to personal issues
Boundaries	- close groups - connected to people's real life - connected to diabetic online community (the two groups in this categories are really connected)	- close groups (exclusive of n. 1 and n. 13) - connected to people's real life	- open groups - connected to people's real life	- open groups (exclusive of n. 7 and 15) - 3 are forums focused only on diabetes and less connected to other aspects of life
Affiliation	- connection to patients associations or websites	- no declared affiliation	- strongly linked to patients groups or association	- no declared affiliation
Immediacy in answer	+++	+++	+	-
Moderation	- really productive puller group - one person that is facilitator and the controller	- puller group - no facilitator or controller (exclusive of n. 13)	- puller person (only the moderator/creator of the group) - no facilitator or controller	- puller person (only the moderator/creator of the group) - no facilitator or controller
Participants	-both type 1 and 2 - both patients and caregivers (but the moderation is provided by caregivers)	-mainly type 1 - both patients and caregivers (mainly patients)	-mainly type 1 - both patients and caregivers	-both type 1 and 2 - both patients and caregivers
Time Framework	- born in 2008/2009 - connections with older closed online groups	Big variety	- n. 10/ new -n. 11/16/17/18 born in 2010/2011	- n. 2/3/4 (forums): 2005/2006 - others: big variety
Size	More than 1000 people	Big variety	200/300 people	less than 100 people (exclusive of n. 3)
Contents	diabetes 360	pragmatic aspects of diabetes management	share info about diabetes and about some real life groups activities	mainly diabetes management and therapies

Briefly, this table states that:

- "In top shape contexts": they are really perceived as groups in which participants feel free to talk about every aspects of their life. Participants feel the context as a protect space in which they found people they trust. A strong puller group maintains always the groups alive and more and more people join the group. Moreover these contexts have strong connections whit all the Italian diabetic community
- "In a discrete manner": they are similar to the previous category but they are felt as less safe places (also because there isn't any a specific group/person that check people and interactions). So people use them in order to receive practical information but there is less participation and less sense of belonging to these groups.
- "Need to keep feet": they can be considered as archive. They are open to all people (even if affiliated to specific groups) and they offer information and services to people or offline groups. We call this category "Need to keep feet" because we think that they are only using few potentialities of these online contexts, instead they could be not only an archive, but a place in which interact, alternative to the offline reality.
- "Out of shape/died": these groups are not really able to support exchanges. This because no one have care of them, they were born without a specific aim, probably just to answer to a momentary problem. So they carry just occasional messages.

4.9 Conclusive remarks

In this chapter we focused on those web applications, forums and Facebook groups, that seemed more able into support interactions and knowledge sharing and construction processes. Anyway, we found many differences in their ability to support these interactions and processes. So we wondered about the possible theories and models framing features of the social contexts supporting knowledge sharing and construction processes.

We chose the "community of practice" model (Wenger *et al.*, 2002) and starting from literature about it, we were able to identify the social and situational dimensions that can frame and differentiate online contexts and their ability to support interactions and knowledge sharing and construction processes.

Starting from these assumptions, in the last paragraphs (4.7 & 4.8) we were able to present what are the characteristics of the online contexts that differentiate them in terms of their ability to support interactions and classifying them toward their degree of "fitness" in support interactions: "In top shape" (supporting a lot of starting posts and interactions and the possibility to share and construct knowledge); "In a discrete manner" (less posts, but good percentage of interactions allowing the possibility to share and construct knowledge); "Need to keep more fit" (many starting posts - sometimes more than the sites in the "in a discrete manner" category- but low level of interactions); "Totally out of shape & Died" (not able to support interactions between participants).

Starting from this categorization we want propose two types of reflection.

Firslty, are all these online contexts considerable as COP?

Probably not.

After the study 1, we were able to consider the online contexts in the interaction area (see Chapter 3) as potential COP, as they present all the needed prerequisite (see paragraph 4.1).

In our opinion, the online contexts categorized as "Totally out of shape" can't be considered as COP.

They don't present two of the characterizing features of COP:

- The joint enterprise: as we said in paragraph 4.7.1, online contexts in this category haven't a shared aim or they just state personal aim.
- The shared repertoire: even if diabetic people share the same experience as patients or caregivers, those online contexts aren't' able to construct their own shared repertoire.

Moreover, also 4 of the online contexts in "Need to keep fit" (10, 11, 17,18) category can be considered just as a repository of a possible offline COP. In fact, they just serve as tools to help offline groups of people to manage information.

So we can say that the analysis we developed allow us to determine which contexts can be considered as online COP. It's important to notice that the reference literature (Dubé *et al.* 2006; Hara *et al.*, 2009) just proposed a typology of COP and not a tool able to distinguish between online contexts able to be defined as COP or not.

Practically, we can say that the dimension we found could be a starter point for the construction of a tool able to detect online COP, at least in the case of diabetes and probably, of chronic illness.

Secondly we want to propose some reflections on the dimensions detected as the ones differentiating the considered online contexts:

- 1. Aim: our analysis showed the need to claim a really clear and practical aim. Literature about online COP, and more in general online communities, has well established this point (Brazelton & Gorry, 2003; Kendall, 2011) (as we said just above). We just want to underline the relevance to make the aim really clear and visible for participants. This element can be considered as the statement of the identity of the online context that is a central "actor" (Galimberti, 2011) into shape (and before into allow) the online interaction. Moreover considering specifically the health field, it's important to underline that both the aims that characterize online contexts supporting peer exchanges about health, namely the research of information and the request for support (Ancker *et al.*, 2009) are present in the declaration of aims of those contexts that show a good level of fitness (n. 6 & 9). This probably means that diabetic patients and their caregivers look for contexts able to provide both types of help.
- 2. Boundaries: participants need a safe context in which share their problem and experiences linked to diabetes and its impact on their life. This probably particularly true because they talk about their health (Newman et al., 2011). Anyway, literature about online contexts (not directly online contexts in which patients interactions occur) underlines the importance of the "trust" as a ground dimension for the good functioning of online context. Trust can be defined as "willingness to be vulnerable, based on positive expectations about the actions of others" (Bos, Olson, Gergle, Olson, & Wright, 2002, p. 1). It's evident how important is the feeling of participate into a close and safe context of interaction in order to favor trust. On the other side, the study underlines the importance of the online context to be connected to others aspects of the life (both online and offline) of the participants making the different contexts more and more interconnected. Internet and online exchanges contexts are no longer vehicle of people different identities and behaviors (as they were 10 years ago, see for example Suler- 2004- that discusses about the "online disinihibition"

- effect") but just one of the context in which we play our life and we create our identity (Galimberti, 2011).
- 3. Affiliation: literature about online health exchanges usually consider exchanges happening in group built ad hoc by researchers or sponsored by medical centre (e.g.: Frost, & Massagli, 2009). Instead, our study shows the relevance to built contexts that patients feel as free from every kind of marketing sponsorship, even if credible. To manage the affiliation of the online context is again a trust matter: pharmaceutical industries are always perceived as an enemy. Instead patients associations who guarantee for the online context can help the construction of trust between participants (the acknowledgement of shared experiences outside the online environment is a possible indicator of trust towards other participants in the interaction- Green, 2007).
- 4. Immediacy in answers: this can be considered as a practical indication of what the psychosocial studies on the computer-mediated interactions call "social presence", namely "the feeling to be with others selves in a real or virtual environment, as the result of the ability to intuitively recognize others intentions in the environment" (Riva, Milani, & Gaggioli, 2010, p. 45). The feeling of social presence is given by the recognition that there is someone else able to answer to my request. It affects the possibility that a person engages in the interaction (Biocca, Harms, & Burgoon, 2003).
- 5. Moderation: we detected three main types of moderation: the "puller" who actively and continuing participates in the interactions; the "facilitator" that helps into solve practical problems and the "controller" who checks the exchanging, deleting uninvited and offensive people or messages. Online contexts that are "In a top shape" category present all the three types of moderation. The three types of moderation can be explained by two concepts we presented above. The first one is "social presence" (Biocca *et al.*, 2003). As we said above the perception of someone else in the online context that may answer to other request is really important. So a person or a group of people ("puller") that steadily participates into the community and to answer others questions (also practical)("facilitator") can be considered as an indication of social presence. The "controller" instead guarantees the possibility to maintain "trust" toward the online context and the other participants.

- 6. Cultural diversity: firstly, as we already stated in Chapter 3, even if both patients and caregivers perceive similar issues connected to the diabetes, the first ones are more interested into the help about problems connected to the diabetes in their daily life, instead caregivers need more support. This is important to consider this factor in the development of possible empowerment strategies for these actors. Moreover we also detected that the main parts of the participants involved in the online interactions seem to be quite adherent to their therapies and interested into improve their care management. Even if literature states that online help to reach every patients (Turner, Kabashi, Guthrie, Burket, & Turner, 2011), we have to reflect on the real possibilities that this type of channel gives to us and on the (implicit) selection of the online interactions participants
- 7. Time framework: we understand that online contexts need time before being able to allow interactions. Again we think this is a matter of trust toward the online context and its participants that need time to be built (Riegelsberger, Sasse, & McCarthy, 2005).
- 8. Size: it seems that contexts presenting an high number of participant support more interactions. We think this dimension, too can be explained by the perception of social presence. The more an online context presents interactions (also by the "puller"), the more people enroll to that group as they feel social presence, the more seeing many people enroll to a group increase the perception of social presence.

It's evident that the dimensions we found are strictly connected to three main concept: trust (Green, 2007; Riegelsberger *et al.*, 2005), social presence (Biocca *et al.*, 2003) and online identity building (Galimberti, 2011).

We think the value of this study is the possibility to shape a first indicator (composed by the above main dimension) of the fitness and the health of the online contexts that explain their ability to support interactions. Moreover it puts togheter many different aspects, as the majority of studies focuses on single aspects.

Starting from this analysis, in the next chapter we will deepen the study of the "In top shape" contexts in order to understand how knowledge sharing and construction processes work.

CHAPTER 5

Analyzing knowledge sharing and construction processes

5.1 Preliminary remarks

This chapter will describe Study 3 in which we'll focus on the understanding of the process of online knowledge sharing and construction. By study 1 and 2 (chapter 3 and 4) we were able to define where (in terms of both technical and social aspects of the contexts) online knowledge sharing and construction processes happen and what characteristics of the context facilitating the online interactions about diabetes. Now we will focus on those interactions (the one that happen in the online contexts considered) in order to understand how knowledge sharing and construction processes happen.

5.2 Online knowledge sharing and construction processes

To do this we will briefly review literature about online knowledge sharing and construction and its functioning. As already stated, literature about online peer exchanges regarding health doesn't deal how patients construct knowledge (O'Grady *et al.*, 2008) ²⁵. Again literature about learning processes (in a socio-constructivist perspective) will help us to frame the topic of knowledge sharing and construction processes.

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²⁵ Anyway, a little branch of literature about online peer exchanges in health deals with the ways in which people give and exchange social and emotional support (Kvasny, & Igwe, 2008) in the online context. We will use it for the construction of the analysis tool for this study (see paragraph 5.4).

5.2.1 What is knowledge?

Let's start talking about knowledge. In COP approach (and more in general in a socio-constructivist perspective) knowledge is not a monolithic object (Wenger *et al.*, 2002), but knowledge has been classified at least according two main dimensions.

Firstly, in the COP studies is central the differentiation between explicit and implicit (or tacit) knowledge. Implicit knowledge "is not easily codified and transferred by more conventional mechanisms such as documents, blueprints, and procedures. Tacit knowledge is derived from personal experience; it is subjective and difficult to formalize. Therefore, tacit knowledge is often learned via shared and collaborative experiences; learning knowledge that is tacit in nature requires participation and doing" (Foos, Schum, & Rothenberg, 2006, p. 7).

The advantage of situated social learning (COP is the context in which it happens) is the possibility to share and learn also the implicit aspects of knowledge from the sharing of experiences and information, the comparison of those experiences and the negotiation with other people in the COP.

Literature established that the exchange and construction of implicit knowledge is possible in online COP too; in fact it is observable and understandable from practices but also from interactions that occur between COP members (Hemetsberger, & Reinhart, 2006).

The second classification of knowledge in COP literature concerns to the type of knowledge: knowledge is not just know something (know what or declarative knowledge), but means also to know (Huang, & Yang, 2009):

- How (Procedural knowledge): knowledge regarding the steps and the procedures.
- Why (Causal knowledge): knowledge regarding causes and effects.
- When (Conditional knowledge): knowledge regarding conditions and contexts.
- Pragmatic knowledge: knowledge regarding practices and application of this knowledge to reality.

If we consider COP of patients, all these types of knowledge are really important and can be object of exchange, as they don't discuss about abstract knowledge but about practices and ways of care management.

5.2.2 Knowledge sharing and construction: the processes

As we said in the last paragraph knowledge sharing and construction in COP are theorized as participation and reification, but it will be interesting to reflect on how these processes practically happen: how they work and function.

Literature studies these processes according to two main perspective: temporal development of knowledge sharing and construction, and discoursive acts.

Studies on the temporal development of knowledge sharing and construction processes are aimed to understand what are the steps of the knowledge construction.

Literature shows too main models: 1. Gunawardena, Lowe, and Anderson (1998), and 2. Garrison Anderson, and Archer (2001). Even if they are quite old in the field of internet studies and refer to Web 1.0, they continue to be the most used (Koh, Herring, & Hew, 2010).

Let's discuss them. *Figure 5.1* proposes Gunawardena, *et al* (1998) model and it is retrieved from Skinner (2007). *Figure 5.2* proposes Garrison, *et al* (2001) model and it's retrieve from Koh et al. (2010).

	Phase
1	Sharing or comparing information
2	The discovery and exploration of dissonance or inconsistency
	among ideas, concepts or statements
3	Negotiation of meaning/co-construction of knowledge
4	Testing and modification of proposed synthesis or co-construction
5	Agreement statement(s)/applications of newly constructed meaning

Figure 5.1

Knowledge construction
Level 0—share information
Level 1—triggering event
Level 2—exploration of ideas
Level 3—integration of ideas
Level 4—resolution of ideas

Figure 5.2

The two models are really similar. Substantially, they focus on three main moments of development of knowledge sharing and construction. Firstly, both models start from the sharing of information and experiences, even if, in the Garrison *et al.* (2001) model, this activity is elicit by a practical problem. This problem step is focal because all the process is done in order to solve it. Then people put together, discuss, reflect and negotiate on the information. This part - one phase for Gunawardena *et al.* (1998) and two for Garrison *et al.* (2001) that divides exploration and integration activities – is the one in which new knowledge is built.

Finally, the new knowledge is tested and at least attemptly applied.

Secondly, the literature has focused on the different discursive activities that support the knowledge processes.

In this case there is not a shared model but different studies that tried to define how knowledge sharing and construction discursively work.

We tried to schematize the main discursive and argumentative types, considering the different temporal phases of the process (see *Table 5.1*).

Phase	Discoursive acts		
1 - Sharing	Solicitation (Hara, & Hew 2007)		
knowledge &	• Seeking help (Nor <i>et al.</i> , 2010)		
triggerng event	• Seeking feedback (Nor et al., 2010)		
	 Asking a question (Skinner, 2007) 		
	• Exchaging resources and information (Nor et al., 2010)		
2- Negotiating	• Suggest (Caballé et al., 2009)		
and elaborating	• Agreeing (Caballé et al., 2009)		
	• Disagreeing (Caballé et al., 2009)		
	• Help giving (Nor et al., 2010)		
	• Feedback giving (Nor et al., 2010)		
	• Challenging other (Nor et al., 2010)		
	• Criting (Zenios, 2011)		
	• Explicating (Zenios, 2011)		
	 Questionning (Pena-Schaff 2004) 		
	• Replying (Pena-Schaff 2004)		
	• Clarifying (Hara, & Hew 2007)		
	• Interpreting (Pena-Schaff 2004)		
	• Conflict (Pena.Schaff 2004)		
	 Negotiating (Pena-Schaff 2004) 		
	• Revising others' point of view (Murillo, 2008) (Repetto, 2011)		

3- testing and	• Judging (Pena- Schaff 2004)
applying	• Reflecting (Pena-Schaff 2004)
	 Making an explicit mention of a new understanding (Murillo, 2008)
	 Self questioning caused by reading the group (Murillo, 2008)
	• Systematizing (Repetto, 2011)
	• Applying (Skinner 2007)
	 Conclusion making (Jahnke, 2008)

Table 5.1 –Discourse activities in the knowledge sharing and construction processes

We think that this descriptive grid could be useful to understand what are the dynamics that allow knowledge sharing and construction. This descriptive point will be useful to understand these processes in other contexts, such as patient interactions. It's also important to point out that literature on peer exchanges and interactions about health and, in particular, about patient online communities focused on similar activities in the study of emotional and social support. Two main examples: Falcone (2010) categorized type of messages in the patient exchanges and the categories proposed seem really the ones above describe, such as messages asking for or supplying similar to information, messages with expression or request of personal opinions, messages aimed at asking or giving support as reassurance, encouragement, demonstrations of esteem or friendship, storytelling messages where people tell of their personal experiences, thanks messages; and emotional messages. Kvasny and Igwe (2008) focused instead on the construction of social identity about AIDS and some of the codes used to identify different conversational actions are really similar o the ones in Table 5.1, such as "Signifying", namely "constructing new terms for talking about AIDS in a culturally salient way" (p.585), or Co-signing "expressing strong agreement with or building *upon a previous comment*"(p. 585)

One last short reflection is about the mode in which knowledge is shared and constructed. Some attention has given to tools used for the learning and knowledge construction processes, in particular comparing textual and visual elements (Janssen, Erkens, & Kanselaar, 2007). Even if text remains the main important mode for knowledge sharing and construction and for, more in general, the all the COP activities, images and in particular videos can be good medium of knowledge, in particular procedural and tacit knowledge (Harley, & Fitzpatrick, 2009). Even if the growing

attention on this topic, it's not clear the role of different communicative mode in the sharing and construction of knowledge.

In our eyes, this rich field of study has two main gaps that need to be filled in:

- 1. All these studies are developed in the educational and in few cases (Hara, & Hew, 2007) in the organizational context. We don't know if the dynamics of knowledge sharing and construction processes can be different considering other fields (and we want to know it!).
- This branch of literature mainly consider online knowledge sharing and construction processes in the online asynchronous forum. We don't know if and how the processes and their functioning varies in other online contexts (such as Facebook groups).

5.3 Aims

In this study we focus on the **process** and on **the functioning** of online knowledge sharing and construction about diabetes. We are interested into understand how knowledge sharing and construction works in online interactions between diabetic patients and their caregivers. Starting from the previous literature review, the study is aimed to:

- a. define the knowledge sharing and construction temporal development and its main phases.
- b. Understand the main interactive (discursive and conversational) dynamics of knowledge sharing and construction processes between patients.
- c. Specify the role of different mode/channel of communication (e.g. the use of picture and images) in the knowledge sharing process.
- d. Describe the main contents dealt in knowledge sharing and construction processes.

5.4 Method

5.4.1 Data collection

By study 2 we were able to identify two online contexts, both Facebook groups, which seem the most able into support knowledge sharing and construction processes.

According to their social and situational features, they were really similar (see Chapter 4); instead they differ for the actors mainly participating to the exchanges. In fact, one of the groups is mainly used by parents of children with diabetes (caregivers); instead the second group is used by both patients and caregivers (adults and children caregivers).

In our study, we considered all the messages posted in the Facebook groups in October 2012 for a total of 7673 messages.

5.4.2 Data analysis

The analysis has been divided in four main steps, according to the aims of the study.

The first was a pre-step, in which we distinguish knowledge sharing and construction processes between other types of interaction. To do this we refer to the theoretical definition of knowledge sharing and construction processes: those processes "where individuals mutually exchange their (implicit and explicit) knowledge and jointly create new knowledge" (van den Hoof et al., 2003, p.)²⁶. So, in our analysis we didn't consider all those interactions in which was not possible to detect the sharing of opinions, experiences, ideas. Moreover, we want to underline than in our analysis we conceive knowledge as:

an accumulation of experience—a kind of "residue" of their actions, thinking, and conversations— that remains a dynamic part of their ongoing experience. This type of knowledge is much more a living process than a static body of information. Communities of practice do not reduce knowledge to an object. They make it an integral part of their activities and interactions (Wenger *et al.*, 2002, p. 9).

According to this definition the sharing of experiences and opinion is part of the sharing of knowledge.

²⁶ We don't report the all the different definitions about these processes provided in chapter 1 (see table). In our opinion, the definition reported here well clarify the concept.

Second step concerned with the analysis of the functioning of the process of knowledge sharing and construction, focusing on: 1. Temporal development of the processes; 2. Interactive dynamics (discursive and conversational) (aim a & b, see paragraph 5.3) We developed an ad hoc analysis grid²⁷. We started from literature review about the online knowledge sharing and construction (mainly applied in learning field) (see *Table 5.1*); then we completed it by considering literature about discursive acts in online exchanges about health (e.g.: Falcone, 2010). Finally we applied and adapted it to our data by preliminary analysis. Briefly, we explain the process of grid adaptation from literature and the codes we used for the analysis. We will propose literature definition, or its adaptation to online knowledge sharing about diabetes, and some quotations from the analyzed messages in order to make more clear the meaning of each code.

According to the aims of the study, the grid considered:

- 1. the temporal development of the knowledge sharing and construction processes. We categorized post basing on 3 main phases (see paragraph 5.2):
 - a. sharing & triggering event: participants tell to others their experiences, information, and practices and/or they present a question/problem (starting from knowledge sharing);
 - b. negotiating and elaborating: it "includes negotiation or clarification of the meaning of terms, identification of areas of agreement, and proposal of a compromise or co-construction" (Kanuka, & Anderson, 1998, p. 64).
 - c. testing and applying: people arrive to state new shared knowledge or directly to apply it.
- 2. Discursive acts of the different knowledge sharing and construction phases:
 - a. Sharing & Triggering event phase:

i. Solicitation, namely requesting for ideas (Hara, & Hew, 2007) towards specific situation (e.g.: "ma il cambio di stagione sballa le glicemie????"
 [Does temperature make glycemic index wrong?])

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First reflections about the development of this analysis tool has been presented in: Libreri C., Graffigna G. (2012) Catching online patients exchanges: a tool proposal. In Graffigna G., Morse J.M, Bosio A.C. (Eds) Engaging People in Health Promotion & well-being. New opportunities and challenges for qualitative research. Milano: Vita&Pensiero. ISBN 978-88-343-

- ii. Seeking help: namely "seeking assistance from others" (Nor et al., 2010, p. 55) (e.g.: "vorrei essere un pò rincuorata da qualcuno ke è riuscito ad avere un figlio sano..in futuro vorrei averne, e il ginecologo un pò mi ha spaventata..." [I want to be reassure by someone who ha san healthy child... in the future I want to have child and my gyn scared me a bit)
- iii. Seeking feedback: namely "seeking feedback to position advanced" (Nor, et al., 2010, p. 55). In the analyzed messages required feedback is about knowing if others had the same experiences or problems (e.g.: "Ciao Ragazze, vi è mai capitato di sentirvi dire dalla vostra bimba/o che ha la tachicardia indipendentemente dalla glicemia?" [Hi girls, does your child feel tachycardia irrespective of his/her glycemic index?])
- iv. Require personal opinion (Falcone, 2010): similar to solicitation, but in this case, the request is directed specifically to a person or a group of people (e.g.: "Per le mamme che utilizzano il vaccino antinfluenzale omeopatico, potete indicarmi il nome?" [For the mums that use homeophatic flu vaccine, can you tell me the name?])
- v. Asking a question (Skinner, 2007) toward a practical and real problem (e.g.: "cose la esoforia???cosa devo fare?" [what is exoforia? What shold I do?])
- vi. Share personal experience (data driven), namely share with others' something about personal experience connected to diabetes (e.g.: "oggi pre pranzo 73 allora un pessetto di strudel pie;)" [today befor lunch 73, so a little piece of strudel pie])
- vii. Sharing information (data driven), namely share information about everything connected to diabetes, such as events, news about therapies (e.g. "ciao a tutti..questa è un azienda che produce cibi per i diabetici" [Hi everybody, this is a company that produces food for diabetic people])

b. negotiating and elaborating phase:

i. Asking for clarification (data driven): to require more information about someone other's post (e.g.: "Sai che non ho capito, cerottino o sensore?"
 [I don't understand, sticky or sensor?])

- ii. Giving clarification, namely, "giving more pertinent details about a topic" (Hara, & Hew, 2007, p. 247) (e.g.: "x xxx si io mangio a cho fissi e mi sono attenuta a quelli...e x la verdura eravamo in un gruppo a menù fisso pizza e bibita e mi sono adeguata" [for xxx, io eat basing on fix cho and I comply with them... and about vegetables, we were in a group that had fixed menù, pizza and drink, so I adapted to it])
- iii. Suggesting (Caballé, *et al.*, 2009): giving advices towards the topic of discussion (Prova a non fumare,non mangiare cioccolato e niente prodotti con caffeina. Vedi che i disturbi spariranno.:))
- iv. Agreeing (Caballé, *et al.*, 2009): people express to feel/act as what others state in previous posts (e.g.: "*perfettamente d'accordo…il micro non deve essere un'imposizione*…" [I totally agree… insulin pump is not an obligation])
- v. Disagreeing (Caballé, *et al.*, 2009): people express to feel/act differently than what others state in previous posts (e.g.: "non sono d'accordo xxx!!" [I don't agree with XXX!!])
- vi. Sharing personal experience and opinions (data driven): people personal experience and opinion connected what others said (e.g.: "Io parlo per la mia esperienza. in quasi 4 anni di diabete non ho mai visto reazioni delle glicemie con i prodotti omeopatici" [My talk is based on my experience. In almost 4 years of diabetes I have never seen glycemic reactions to homeopathic products])
- vii. Sharing information (data driven): sharing information connected what others said (e.g.: "Vi segnalo un articolo del Corriere della Sera sui farmaci a scuola" [I advise an article publishe on Corriere della Sera²⁸ about drugs at school])
- viii. Help giving, namely "responding to questions & requests from others" (Nor et al., p. 55) (e.g.: "Mi permetto di dare un ulteriore consiglio per star lontano dai guai, cioè dalle IPO" [I take the liberty to give an advice to stay away from troubles, namely hypoglycemia])

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²⁸ One of the main Italian newspaper.

- ix. Feedback giving, namely "providing feedback on proposals from others" (Nor et al., 2010, p. 55) (e.g. "Hai ragione, sono pienamente daccordo con te, dovrebbero essere amorevoli e comprensive, invece sono sempre rigide e incomprensive ..." [You're right... I totally agree with you, they should be lovely and sympathetic, instead they are always strict and severe])
- x. Judging (Pena-Shaff, 2004): give a judgment toward possible therapies, or a research centres or diabetes management solutions (e.g.: "è uno strumento terroristico. fa esattamente ciò che descrivi. se vuoi avere guai usalo. pensa che in veneto neanche ti dicono che esiste tanto fa schifo." [it is a terrorist tool. It does exactly what you describe, if you want trouble, use it. It sucks so much that in Veneto no one tell you that it exists])
- xi. Criticing: Zenisos (2011) defines it as "to fashion a discourse such that a person who partakes of that discourse becomes aware of the good and bad points" (p.262) of what he/she said.
- xii. Revising other's point of view (Repetto, 2011), namely the activity of rethink and reformulate contributes stated by others

c. testing and applying phase

- i. "Acknowledging learning something new" (Pena-Shaff, 2004, p. 255), more practically Murillo describe this type of act as "making an explicit mention of a new understanding" (Murillo, 2008)
- ii. "Acknowledging importance of subject being discussed" (Pena-Shaff, 2004, p. 255) (e.g.: "Grazie è stato davvero utile parlarne" [thank you, it was really useful to talk about it]
- iii. Discussing about application (Skinner, 2007) of the knowledge shared and/or constructed (e.g.: "allora faccio prima la rapida?"[Do I iniect rapid insulin first?])
- iv. Statement of application (data driven): expressing to have applied the knowledge shared and/or constructed (e.g.: "Alla fine ne ho mangiato mezzo come mi ha detto xxx" [Finally I ate just one half as xxx told me]

- v. Conclusion making (Jahnke, 2008): state conclusions starting from the knowledge shared and/or constructed
- 3. Discursive acts related to social and emotional support. Because social and emotional support are central into online patient exchanges (and this aspect was evident also by preliminary analysis), we chose to consider if and how discursive activities typical of social and emotional support oriented interaction are used.

a. Social discursive acts

- i. Thanking, namely "offering thanks for some action" (Hara, & Hew, 2007, p. 246) or comment provided (e.g.:"grazie, ottima idea" [thank you, grat idea]
- ii. Greetings (Hara, & Hew, 2007) (e.g.: "Bouna domenica!!!" [Have a nice Sunday!!]
- iii. Explicit mention of belonging to the group (Murillo 2008)
- iv. Explicity use our (Murillo, 2008). For Murillo (2008) these two categories are expressions of a shared sense of community
- v. Direct replying (Pena-Shaff, 2004): directly refer to a specific person or group in the message (e.g.: "proprio te volevo" [I was looking for you)]
- vi. Explicit mentioning of another expertise (Murillo, 2008): directly refer to expertise of another participants of the online context (not directly of that interaction)

b. Emotional discursive acts

- i. Asking for assurance and support (Falcone, 2010) toward practically and emotional difficulties and problems
- ii. Consoling: "seeking consolation from sadness, happiness, or other emotions" (Kvasny, & Igwe, 2008, p. 586) (e.g.: "ho tanta paura" [I'm really afraid)]
- iii. Giving support and consolation (Falcone, 2010) after request
- iv. Encouraging (data driven) help others by stating they will be able to face diabetes (e.g.: "tieni duro Tesoro" [Hold on, honey]).
- v. Expressing empathy (Graffigna, 2009): comprehnsion toward others' happiness or pains (e.g. "XXX ti capisco benissimo..." [XXX I totally understand you...])

- vi. Using humour (Falcone, 2010)
- 4. We also considered possible communication problems (Graffigna, 2009)
 - a. Flaming
 - b. Misunderstanding

Thirdly, we developed a multimodal analysis (aim c, see paragraph 5.3) (Herring, 2010). Starting from the assumption that online communication is not text but more and more it use pictures, videos, links (Herring, 2010), we analyzed the use of these different modes of communication in online knowledge sharing processes, considering:

- a. Sequentiality (e.g. are there specific patterns of messages for the use of different modes of communication?) (Goodings & Brown, 2011)
- b. Relationality (e.g. how are messages developed by different modes connected?)(Goodings & Brown, 2011)

Finally, content textual analysis was provided using T-Lab software. Contents of interactions were analyzed, according to the main following variable:

Types of knowledge sharing and construction process.

Final version of the grid is presented in *Appendix D*.

5.4.3 The softwares

The storage of data and the two first steps of analysis were supported by Nvivo 10 (see Chapter 2, paragraph 2.5).

Moreover, content textual analysis was provided using T-Lab software (see paragraph 2.5).

According to our aims, we chose to use the following technical options:

• Thematic analysis of elementary contexts: it gives a "representation of corpus contents through few and significant thematic clusters" (Lancia, 2012, p. 64) by a complex procedure that joints co-occurrences analysis and comparative analysis. We used it to obtain an overview of the analyzed knowledge sharing and construction processes.

- Word association: by co-occurrences relationships analysis, it allows to determine the "local meaning" (Lancia, 2012) of a selected word. The analysis is carried out by the computation of an Association Index (Cosine, Dice, Jaccard). We used it to understand the perspective by which online knowledge sharing and construction processes dealt with diabetes.
- **Specificities analysis**: as already described in chapter 3 (see paragraph 3.4),it defines which lexical units (words or lemmas) are the most typical lemmas (over-used lemmas) and those which are typically absent (under-used lemmas) in a text subset (defined by a variable) (Graffigna, 2009). Practically, we used it to compare contents produced by different knowledge processes.

5.5 Sample description

We analyzed the interactions happened in the two Facebook groups considered the protypical online contexts for the development of online knowledge sharing processes about diabetes.

Briefly the online contexts we considered: are really similar for their social and situational features (see Chapter 4), but they differ for the actors of the exchanges. Both of them hosts online exchanges about diabetes among patients and caregivers, but the n. 1 (that was numer 6 in Chapeter 4) is mainly focused on caregivers exchanges: in particular, it hosts mums and some dads of diabetic children; few are the contributes of patients (often they are mums and diabetic). Because of the target, the messages and interactions mainly deal with diabetes 1 (more typical in childhood than type 2). The group n. 2 (that was number 9 in Chapter 4) hosts both patients and caregivers and both diabetes type 1 and 2.

Table 5.2 describe the sample of messages analyzed.

	1	2	TOTALE
Total n. of	4236	3437	7673
messages			
N. of starting	492	298	790
messages ²⁹			
N. of started	156 (31% of starting	81 (31% of	237 (30% of
messages without	messages)	starting	starting
answers		messages)	messages)

Table 5.2 – Sample description

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²⁹ We refer to those messages that start a new discussion.

Table 5.2 shows the number of messages analyzed. Then we reported the number of starting messages and finally the number of starting messages that received answer, who corresponds to the number of the interactions or discussions activated in the two online contexts during the period considered.

It's evident from this table that both the online contexts host an high number of discussions (around 70% of starting messages receive answers). This is really important as interactions allow the possibility of knowledge sharing and construction.

5.6 Detecting knowledge sharing and construction processes

Before starting the presentation of the knowledge sharing and construction processes about diabetes, we will clarify what messages we analyzed.

First of all we didn't consider starting messages without any answer. It's evident that any type of knowledge sharing and construction process may happen there.

Then we wondered: can all interactions occurred in the analyzed online contexts be considered as knowledge sharing and construction processes?

In our opinion, and also for the literature (Zheng, & Spires, 2011), not all the interactions are knowledge sharing and construction processes.

As stated in method section of this chapter (see paragraph 5.4), we started from the theoretical definition of knowledge sharing and construction processes: those processes "where individuals mutually exchange their (implicit and explicit) knowledge and jointly create new knowledge" (van den Hoof et al, 2003, p.) in order to detect the knowledge sharing and construction processes.

So in our analysis we didn't considered the following categories of interactions and messages:

• "Mono –discussions" (2% of starting posts; 4 % of the total messages) in which one person posted the starting message and then commented it. It is quite clear that no peer dimension exists here. (Example: a participant posts this comment "Ho cannato... Primo allenamento di hockey aveva glicemie buone così ho fatto meno insulina a merenda per arrivare altino e non correggere.... 324 un po' tanto altino?!!!!!! Boh ora e' dentro ed e' una gioia vederlo!! Come mi mancava il ghiaccio!... E anche a lui! Non ho osato correggerlo!... Vediamo dopo!...ciao

amiche" [I did wrong... first hockey training and he had good glycemic level so I did less insulin in the afternoon in order to arrive quite high and not correct...324 too much high?!!!! Now he is inside and it's a joy to look at him!! How I miss ice!.. and him too! I wasn't able to correct!... We will see later... Bye friends]- Then after the hockey training the same person says "Evvai fine allenamento 126!!!" [Yuppie, after training 126!!!]- Then before the nnight she sayd "Cavolo adesso ipo ©" [Damn, now hypoglycemia])

- Out of topic (4% of starting posts; 4,5 % of the total messages) because it comprehends few exchanges not relevant in terms of diabetes and knowledge processes. ("voglio l'estate ho freddooooooooooooooo" [I want summer I feel coooollllddd]). They were out of the "domain" (as stated in Chapter 4 the contexts we considered can be considered COP that have diabetes as their domain).
- Greetings and social messages and interactions (16% of starting posts; 9 % of the total messages): participants use a lot of social messages, such as greeting s and rewards about the group relevance ("Buon week end lungo e ci si vede lunedì con tante tante foto!" [Have a good week end and see you on Monday sharing a lot of pictures]). We didn't consider this category as the interactions in this category are aimed to show presence and importance of the groups in people lives and to maintain good relationships between members ("ma quando si trovano persone "uguali a te" con le quali condividere stesse emozioni, sensazioni, problematiche ma anche speranze, gioie o semplicemente trascorrere un week-end insieme, tutto è più "leggero" e la vita ti sorride e nn ti senti "solo" nel sopportare e portare questo pesante, ingombrante, fastidioso zaino sulle spalle. Vi abbraccio con immenso affetto <3" [when you find people like you when you can share the same emotions, feelings, troubles, but also hopes, joy or simply stay together for a weekend, everything is "lighter" and the life smiles to you and you don't feel alone into bring this heavy, bog and annoying backpack we have on our shoulders]). Messages in this category seem to not bea imed to support knowledge sharing and construction processes
- "Good-great" interactions (25% of starting posts; 10 % of the total messages): this label derives from the fact that these interactions are characterized by the continuous use of good, great beautiful... Practically, we refer to those interactions in which

participants make only appreciations of the content (or the author) of the starting message.

Example:

- 1. BENISSIMISSIMO EMOGLOBINA DA 8.6 A 7.3......
- *3.* :)
- *4. wowwwwww....bravissime!!!!!!! <3*
- 5. <3

[1 GREAT GLYCOSYLATED HAEMOGLOBIN FROM 8.6 TO 7.3

- 3.:)
- 4. wowwwwww... very good
- 5. <3]

We know that this type of interactions is really important for patients are caregivers, because it expresses social and emotional of support, but we can't considered them as knowledge sharing and construction processes as any type of knowledge, experience or opinion is shared

So finally we considered in our analysis of knowledge sharing and construction processes:

- 4649 messages (61% of total messages)
- 220 starting messages followed by answers (40% of total starting messages followed by answers) that means we considered 220 knowledge sharing and construction processes

Let's move now to present and discuss knowledge sharing and construction processes.

5.7 Knowledge sharing: the perspective on diabetes

Before to explain how online knowledge sharing processes work between diabetic patients and caregivers, we want to present some results that better explain what the perspective on diabetes dealt by these processes is.

By content textual analysis (see paragraph 5.4 of this chapter) the main aim of these processes seems to be "understand life with diabetes"

Figure 5.3 shows the words more associated with diabetes (the analysis was provided by T-lab, see paragraph 5.4).

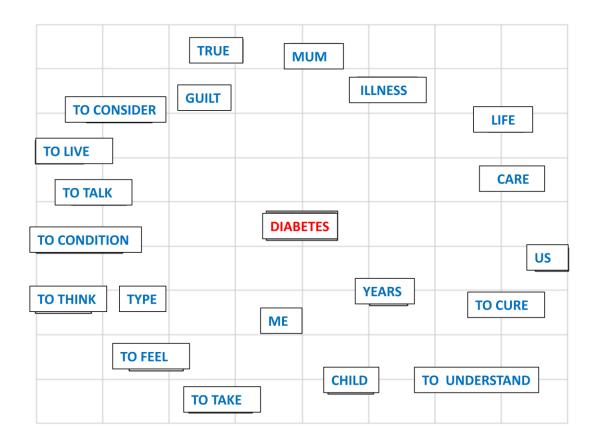


Figure 5.3 – Diabetes words associations

According to this analysis, the main needs toward diabetes are:

- To think and talk about diabetes: practically participants need to have a place to discuss and reflect about their diabetes, because they can't do it in their everyday life (e.g.: "ho bisogno di parlare di diabete e a stare in contatto con chi vive quello che vivo io" [I need to talk about diabetes and to stay in contact with people that live what I live])
- To understand diabetes: what symptoms, what correlated disease, what new therapies ("potrà essere che non a tutti l'ipo dia gli stessi sintomi??" [Could hypoglycemia present different syntomps in different people?]
- To live and manage diabetes: concerning all the practical aspects of life that diabetes affects ("nei file c'é uno scritto di xxx che spiega come fare a trovare il rapporto insu/cho" [between the files there is one written by xxx that explains how to find the ratio insulin/cho])

Moreover, by using thematic analysis of elementary contexts (supported by T-lab, see paragraph 5.4 of this chapter), we created a map of the main contents dealt by knowledge sharing and construction processes (*Figure 5.4*).

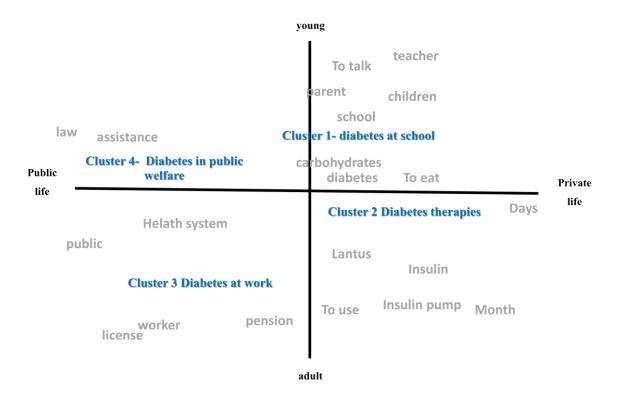


Figure 5.4- Main Contents Map

The map is based on two main dimensions:

- Public vs private management of diabetes: management of diabetes regard aspects of public life (left pole), such as at work, during social activities and toward laws; and it regards private life, in particular the management of therapies and diet³⁰.
- The lifecycle: childhood and adult life concern with different problems in the management of diabetes.

Within this map, starting from thematic analysis of elementary contexts (supported by T-lab, see paragraph 5.4 of this chapter), it's possible to identify 4main clusters connected to diabetes management:

³⁰ This is different from study 1 as this dimension concerns with aspects of private and public life of diabetic patients and their caregivers.

- 1. Management of the diabetes at school: in particular the relevance to talk with teacher and to have their help in the management ("Oggi primo giorno di mensa di Asia all'asilo da sola... Ke Dio ce la mandi buona..." [Today is the first day Asia eat at the kindergarten alone... hoping everything will be good])
- 2. Diabetes therapies: in particular the use of insulin pump and the carbohydrate count ("Lo schema ora e': 4 insuman al mattino, 4 humalog a pranzo (no insuman perche va a fare sport) e 1-1.5 massimo 2 a cena lerche... E poi 15-16 di lantus ore 22" [The schematic now is: 4 insuman in the morning, 4 humalog at lunch (not insuman because he makes sport) and 1-1.5 or at most lerche at dinner... and then 15.16 lantus in the night])
- 3. Management of the diabetes at work: in particular laws concerning work and legal disability ("io ho il diabete, ho una disabilità dichiarata con la 104, prendo i permessi per le mie visite, allora mi pagano al 100" [I have diabetes, I have declare disability and I have 104, I have authorization to not go to work when I have to go to my check and I'm paid 100%]).
- 4. Diabetes in the public welfare: mainly concerning with the healthcare system. ("LEGGE 19 settembre 2012, n.167- Norme per consentire il trapianto parziale di polmone, pancreas e intestino tra persone viventi" [LAW 19 september 2012, n. 167- Rules for the possibility of partial transplant of lung, pancreas and intestine between living people]).

So knowledge sharing and construction processes deal with 360 degrees of diabetes, concerning with many and different aspects of the management of the illness in everyday life.

If the topics of knowledge sharing and construction processes are clear deal with, we need to understand how they develop and function.

5.8 The knowledge sharing and construction processes

According to the aims of this study, we will present the main phases of knowledge sharing and construction processes. Then we will present that different types of processes exist and we will present their main discursive strategies and the topic they deal with. Before to do this, we want to briefly outline what is the background logic who frames these processes.

5.8.1 The ground logic

Our qualitative and ethnographic perspective, that allows us to go beyond the codes we prepared for the analysis and to plunge into the data, strongly shows a common aim who guide all the processes we analyzed: the will to solve problems. Problems both connected to practical and delimited issues ("320 e 1.3 di ketoni ke faccio?????" [320 and 1.3 ketones what should I do???] or to social and broad questions ("Quanto il comportamento dei genitori influisce negativamente sulla visione della patologia del bambino?" [How much does the parents behavior negatively influence the child perspective on the disease?]); problems that refers both to the cognitive and the informative sphere ("Come è la Novorapid?" [How is Novorapid?]) and to the emotional one ("Care mamme aiuto da stasera cambio cura da: insuman e humulin a novorapid e levemir ho una paura tremenda" [Dear mums, help me this night I change my therapy from insuman and humulin to novorapid and lemir, I'm really scared]. Anyway, the key perspective that grounds the knowledge sharing and construction processes is the **problem solving** perspective.

5.8.2 Knowledge sharing and construction processes phases schematic

Figure 5.5 shows the three main phases of online knowledge sharing and construction between diabetic patients and their caregivers.

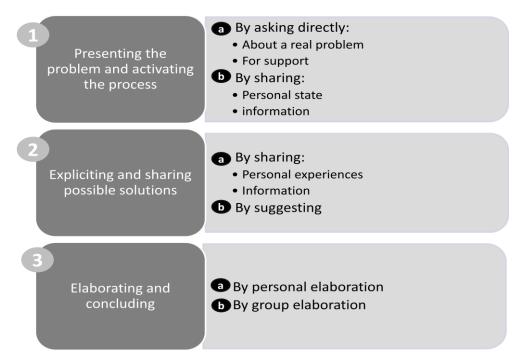


Figure 5.5 Knowledge sharing and construction main steps

Briefly:

- We called Step 1 "Presenting the problem and activating the process". This step is referred to the starting phase of the process. The label refers to the aim of this step, namely to present a problem to solve. It can be done by two main types of strategies: by direct ask of help about a practical and real problem ("Sapete qual'è l'effetto delle castagne sulle glicemie?" [Do you know the effect of chestnuts on glycemic index?]) or asking for support ("Vi prego qualcuno mi dica che sono stata brava ne ho bisognoooooo !!!!!!" [Please someone tells me I was really good because I need it !!!!]) and by sharing personal state ("Noi siamo in crisi. Mia figlia "si dimentica" di fare i controlli..." [we are in crisis. My daughter forgets to check her glycemic index]) or information ("offerta per strisce reattive e lancette pungidito BGstar fino al 31/12" [offer for sticks and glycemia check tools BGstar till 31/12]) In this step the sharing of experiences, information and opinion is a strategy aimed to present a problem.
- Instead, Step 2 "Expliciting and sharing possible solution" is aimed to the sharing activities. The idea is to collect different points of view, in the form of statement of personal experiences ("Io misuro la glicemia a xxx prima di svegliarlo, così se è alta faccio subito l'insulina e nel frattempo che si sveglia e preparo la colazione

l'insulina fa effetto!" [I check xxx glycemic index before to wake him up and so if it's high, I right do insulin and then whil he is waking up, I prepare breakfast and insulin has effect]) or information, or in the form of suggestion ("Io vi direi di cambiare il posto il più possible, anche se è difficile con bambini piccolo" []I suggest you to change the injection area as more as possible, even if it's difficult to it with children]).

• Finally Step 3 "Elaborating and concluding" refers to the activities, both persona and within the group, of elaboration and reflection about the shared knowledge in order to find a solution to the problem (this knowledge can be considered new as it is tailored on that specific problem)

It's important to notice that this is a general schematic. Indeed, we were able to define different types of knowledge sharing and construction processes. Step 1 and 2 are always presented (even if they occur by the use of different interactive strategies), instead NOT all the processes we detected present step 3.

Now we present step 1.

Steps 2 and 3 will be presented for each different type of knowledge sharing and construction detected.

5.8.3 Step 1 Presenting the problem and activating the process

Practically, this step concerns the ways in which the knowledge sharing and construction processes are activated. As already said, the processes start from a problem. From the analysis of the starting messages of each discussion, we defined 4 main strategies for present and introduce a problem, guided by two basic logic (see *Figure 5.6*):

Type of discursive strategies in Step 1	n.	%]	
asking about a real problem	122	55	\	Direct asking: 57%
asking for support	5	2	IJ	Direct asking. 5770
sharing personal state	74	34	<u> </u>	Sharing: 43%
sharing info	19	9	Υ	
TOTAL	220	100		

Figure 5.6 – Step 1 strategies (frequencies and percentage)

- 1. Directly asking (57 % of the total starting messages of knowledge sharing and construction processes)
 - a. Asking about a specific problem (55% of the total starting messages of knowledge sharing and construction processes): participants directly ask questions about problems or hypothetical problems connected to the diabetes management in everyday life, in order to receive help ("astucci termici per conservare le penne da insulina al fresco quando si è in vacanza?consigli?GRAZIE" [thermal bags to conserve insulin when you are on vacartion? Any suggestions? THANKS]);
 - b. Asking for support (2 % of the total starting messages of knowledge sharing and construction processes): participants ask for support when they are struggling with diabetes ("a volte sono cosi' stanca...passeggiate, gite scolastiche, scioperi con lunghe camminate, pizzate, pigiama party con annessa dormita a casa delle amiche, mi viene da piangere..." [sometimes I feel so tired... walks, school trips, protests in which we walk too much, pizza dinners, pigiama parties sleeping at friends' home, I want to cry]). This means not only practical solutions but also, encouragement ("Eddai che andrà tutto bene;-)" [Come on, everything will be good;)]) and consoling ("XXX ti abbraccio forte" [XXX, I give you a big hug!]);
- 2. Sharing (43 % of the total starting messages of knowledge sharing and construction processes):
 - a. Sharing personal state (34% of the total starting messages of knowledge sharing and construction processes): participants share some aspects of their life. They concerns problem in the management of diabetes practical, but also emotional and social- and also little successes, or events in their life connected to diabetes ("che glicemie basse oggi!!!" [such a low glycemi levels today!!!]);
 - b. Sharing information (9% of the total starting messages of knowledge sharing and construction processes): participants share information about news, events, scientific improvements in therapies and books connected to diabetes ("Il Prof. Ricordi intervistato dalla Raia Genova, in attesa della

presentazione del suo libro." [Prof Ricordi will be interwied at Raia Genova, before the presentation of his book]);

As *Figure 5.6* shows the most used strategy is to directly ask about a specific problem. This probably means that participant know they will find the answer they need n the group. This is also confirmed by the fact they refer to specific members of the group when they have specific problem they know that person can cope ("*chiedi a XXX è del campo ti saprà dare tt le info*" [ask to XXX, she is an expert in the field and she will provide all the information you need]).

Anyway, knowledge sharing and construction can start from a simple sharing of a state or information, without the presence of a direct question.

5.8.4 Step 2&3: evolution of different knowledge sharing and construction processes

We showed that knowledge sharing and construction processes are activated by the statement of a problem. What happens after this first step?

Not all processes arrive at Step 3. Moreover their development is based on different discursive strategies.

We detected 5 main types of processes: Just Sharing (experience level), Just sharing (Info level), Suggesting, Personal elaboration, and Group elaboration. The first three of them stop at Step 2 "Expliciting and sharing possible solution". The other two arrive at Step 3 "Elaborating and Concluding", by presenting different types of elaboration.

We will describe the different processes by considering the different discursive strategies used to develop them and the main content they deal with³¹.

1. Just sharing (experience level) (39% of the processes³²): this is the most used process. Practically, after the Step 1, different members of the group share their personal experience about the topic and the process stops in this phase.

In terms of discursive acts, all the different participants tell their "story" (and usually they post a lot of different experiences, even 20 or 30). But there is few "dialogue"

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³¹ Analysis of the content of each type of knowledge sharing and construction process was based on Specificities analysis, developed by using T-lab (see paragraph 5.4).

³² Appendix E will report percentage of each type of process both in term of percentage of discussion and percentage of total messages.

between them. It seems that they don't judge others' experiences; in fact, they agree with others if they share similar experiences. Instead if their experiences are different from the previous, they just tell what they want to say without link it to others' experience.

In terms of contents, this type of process mainly deals with practical private management of diabetes, in particular with treatments and eating (see *Appendix F*). Indeed, this kind of problem is usually just solvable by having insights from someone who already faced it, without building new specific knowledge on it.

This kind of process seems to be helpful for participants and for the person who post the problem because of two main reasons:

- a. it's a quick and trustable manner to know new ways to approach and solve problems. Sometimes, it becomes an archive of possible practices toward a particular problem; for example, we found post referring to previous conversations and the use of insights from those conversations in real life; another example are the "what if" discussions ("Care mamme vi capita mai di pensare a come comportarsi in caso di emergenze alluvioni o terremoti" [Dear mums, do you never think what to do in case of emergencies such as earthquackes or floods?]). In this case, one member, mainly one member of the puller group (see Chapter 5), ask a question about a problem that he/she doesn't really have but that could happen in order to receive suggestions on the ways to face it.
- b. Share experiences are also a way to normalize them. Many times participants need just reassurance about the normality of their problems and experiences, by understanding that others had the same problems. This is a way to solve their problem, so no more steps are required.

Example:

1care mamme c'è qualcuno tra voi che fa il controllo alle 3 di notte, e se lo fate in particolari circostanze..? grazie

- 2. io lo faccio al cambio del set o in casi particolari glicemie alte la mattina febbre ecc..
- 3. io lo faccio quando dopo cena la glicemia nn è buona, se è alta aspetto le 3 e correggo, se è bassa gli dò un pò di zucchero
- 4. io l'ho fatto per un paio di giorni qualche mese fa perchè non si capiva come mai la glice era sempre alta al mattino e i dottori volevano sapere se era un problema della lenta che era poca o se era l'effetto alba
- [1. dear mums, there is someone here that check glycemic index at 3 am in the night, if yes under what specific circumstances?
- 2. I do it, when we change insulin pump set or when morning glycemic level are too high or for the flu
- 3. i do it when after dinner glycemic level is bad, if it's too high I wait till 3 am and I correct, if it's too low I give him some sugar

- 4. I did it for a couple of days some months ago because it wasn't unclear why the glycemic level was high in the morning, if it was connected to slow effect insulin or to the sunrise effect]
- **2. Just sharing (information level)** (15% of the processes): as the previous one, this process consists just on sharing. But in this case people share information and not their personal experiences. Information refers to a specific problem, its features and eventually possible ways to solve it.

In terms of discursive acts, this process is configured by quick and short exchanges (around 3- 4 posts). Substantially after Step 1, participants directly provide information. In this kind of exchanges, emotional component is less present, but participants use humor about information, and news, they don't understand or don't like.

In terms of content, this kind of process is focused on "institutional knowledge", namely that knowledge provided by an institutional or expert source, such as laws, regulations, research, medical information (see *Appendix F*). In this type of process is notable the use of links. This is probably a way make the reported info more trustable, reporting source and exacts words.

Example:

- 1. Ho appena letto che la FDA proprio ieri ha approvato il nuovo sensore CGMS Dexcom G4 PLATINUM! <u>Direct link</u>
- 2. otherlink
- 3. Peccato mostrino solo l'elegante ricevitore e non diano contezza del trasmettitore
- 4. qui dovresti trovare tutto XXX! :) Direc tlink
- [1. I just read that yesterday FDA has approved the new senso CGMS Dexcom G4 PLATINUM! Direct link
- $\overline{2}$. other link
- 3. Unfortunately they just show the elegant device and they don't' give any information about transmitter
- 4. here you can find everything XXX! © direct link]
- **3. Suggesting** (10% of the processes): in this case, people don't share their experience, but they propose possible solutions directly about the proposed problem; these suggestions are usually based on their experiences, but they are an elaboration of them. This kind of process mainly start when someone ask for a specific problem.

In terms of discursive acts, there is much more interaction between the participants in the discussion that in the previous two types. Practically this type of process is characterized by few participants (2 or 3) that ask many questions to the person who proposes the problem. Then based on their analysis of the situation, they provide practical suggestions. They use to direct speak, ask and answer between them by directly saying the name of the person they want to speak with. So it's possible to state that this type of strategies for find possible solution comprehend a joint analysis of the

problem. Moreover, in this type of process, people offer assurance to the person who states the problem; again, these processes are a way to help people to solve their problem, normalizing their situation and to put down their anxiety.

In terms of contents, this type of process is focused on practical problems, such as the "just sharing" (experience level). Moreover, specificities analysis underlines the presence of words such as "to suppose" or "to eliminate" that highlights the process of joint analysis of the problem between the participants to the discussions (see *Appendix F*).

Example:

- 1. non c'è niente da fare..non risco a trovare una soluzione x quando mangio la pizza..anche se faccio il bolo a onda doppia, la mattina è sempre molto alta! =(
- 2. A quante ore imposti la doppia?! Io ora a 5 o 6 ore e funziona! Prima avevo il tuo stesso problema!
- 3. 4 ore e mezzo..
- 4. Dovresti provare a vedere com'è la glice dopo 4 ore e mezza! Se è buona e si alza dopo potresti provare a allungare la doppia! No?!
- [1. Nothing to do.. I can't find a solution for eating pizza... even if I do doble wave bolus, in the morning my glycemic level is always high
- 2. how many hours is long your double wave? Now I do 5 or 6 hours and it works! Before I had the same problem!
- 3. 4 hours and a half...
- 4. You shuld try to check your glycemic index after 4 hours and a half! If it's ok and it grows uo later you can extend the double bolus! What do you think?]
- **4. Personal elaboration**(8% of the processes): this process show step 1 and then step 2 is equivalent to "just sharing" (experience level). Then there is a further final phase in which the one who started the discussion conclude it by stating his/her new knowledge acquisition.

In terms of discursive strategies, participants share their experiences, as for "just sharing" (experience level) type. Then a final feedback is given by the discussion starter (the person who presented the problem). This feedback is given by using two main ways:

- Thanking: in this case, the discussion starter thanks for the advices given, underlying their usefulness
- Telling how the problem/question/story ended: in this case, the discussion starter says what he did/will do (in case of hypothetical problems) or tell how the story went, underlying the importance of the others experiences in the conclusion of the question.

In terms of contents, this type of process is mainly linked to diet and therapies, in particular therapies to face critical events (such as hypoglycemia or insulin correction for hyperglycemia) (see Appendix F).

The person who posed the problem probably does an elaboration of the knowledge shared in Step 2, but the process it isn't evident in the online context. In the online context it's only possible to know the outcome of that process.

Example

- 1. Sono 2 giorni che mio figlio nonostante le correzione viaggia sui 300 e' molto raffreddato il centro non risponde qualche consiglio?
- 2. Fallo bere tanto, controlla i chetoni e,se li trovi, aumenta l'insulina per le correzioni...
- 3. Ciao aumenta le unità di insulina, non avere timore di farlo ..:-)

•••

- 4. Grazie a tutti ho fatto correzione a merenda e adesso vs meglio un po' bassa ma è scesa
- [1. Since two days my son has glycemic levels around 300, even if the corrections, he has got flu, the medical centre don't answer, any suggestion?
- 2. Make him drink a lot, check the ketones and if you find them, do more insulin in the correction
- 3. Hi incrase the units of insulin, don't be afraid to do it..;)
- 4. Thank you to every one I did correction in the afternoon and now it is better, it's now too low but it decreased]
- **5. Group elaboration** (28% of the processes): this is the only type of process in which the elaboration (in the online context) goes over the sharing of experiences, information and suggestions. In terms of flow, step 2 and 3 co occur. In fact, the process hasn't two different steps (clearly temporally divided) but sharing of experiences, opinions and information is concurrent with the elaboration of them.

What it's evident is that this type of process is activated by topic in which people feel really involved (connected for example with their identity) and that present positions that diverge really much. Basing on contents, two main types of process development are retrievable:

Practical issues: in this case, the process is a mix of the previous processes. A joint elaboration, similar at the beginning to the "suggesting" type, begin, based on the sharing of different experiences. This type of process starts with a primary hypothesis of solution by the person who exposes the problem that is tested by the discussion with peers. Few people discuss together, facing a practical problem. The relation is informal, and participants are really kind towards the others and they appreciate the exchanges and underline the importance of the group into help them, even if their opinions may diverge.

Complex and controversial issues: topics that don't deal directly to management of diabetes, but that concern social aspects of diabetes or the notice of new and experimental (and definitive) cures, are usually really discussed in the exchanges of both the two groups. Practically, there are few discussions of this type but they comprehend a huge number of messages. In terms of discursive acts, the group elaboration is a continuous argumenting or counter argumenting of the previous positions. In terms of results, it's difficult then to arrive to a conclusive solution of the problem, but it helps to open people perspective on the question. This is the only type of process in which we found flames, even if just between couple of fighters and not considered by the others ("senza offesa XXX.... ma tu pensi davvero che questo sia il mio intento?! nn hai capito proprio nulla di me! credi sempre di avere la verità in mano?! buon per te... e meno male che nn siamo tutti uguali!!! grazie a Dio!" [no offence XXX... do you really think that this was my intent?you don't understand anything about me! Do you think you always know the truth? Good for you... thanks God we are not all the same!]). Moreover, in this kind of discussions people use a lot humor; this probably because they are issue that touch people deep feelings, indeed these discussions talk about new therapies and hope to heal, or they concern stigma about diabetic people.

Example

1. XXX ha una penna di insulina nello zaino, nel caso ne avesse bisogno a scuola, secondo voi, quanto tempo puo' stare li', visto anche l'ambiente caldo delle classi ??

3. Solo in estate la metto in un contenitore termico con sacchetto refrigerante

...

4. Ma da quanto tempo la tiene nello zaino? Ti sei scritta la data sulla penna?

5. No, buona idea questa! :) io lo facevo con le boccettine , adesso nel giro di 15 giorni l'insulina i esaurisce. Adesso la butto, sono passati circa 20 giorni.

7. eh sì a volte dipende anche da quale tipo di insulina si usa....sempre meglio specificare ;)³³

3. I put it in a thermal bag only in the summer

. .

4. How long does the insulin stay in the bag? Did you write the date on the inslulin pen?

^{2.} Ŝul bugiardino c'è indicata la durata massima di conservazione dell'insulina conservata a temperatura ambiente (tanto nelle scuola non supera mai i 25°). Oltre quella data puoi salutarla.

^{6.} l'insuman rapid và tenuta in frigo(scomparto uova)poi una volta aperta a temperatura ambiente x 20 giorni,non sò tu quale usi

^{[1.} XXX ha san insulin pen in her back pack, just in case she need it at school, how long does it last, considering the hot temperatures in classrooms?

^{2.} Usually they reported maximum lenght for insulin conserved room-temperature. More than that day you can say bye-bye to it

³³ We didn't report all the interactions, even if it's clear they share their information and try to construct a solution on it, reflecting on different possibilities.

5. No, this is a good idea!:) I did it on insulin bottles, but now in 15 days insulin pen finishes. Now I throw it out, it's more than 20 days

. . .

We want to propose two more reflections about the different knowledge sharing and construction processes.

Can the different strategies adopted in Step 1 be linked to the different types of knowledge processes? (*Table 5.3*)

	,	g about problen		8	asking f			sharing sonal s		sł	naring in	fo		тот	
	n.	row %	Col %	n.	row %	Col %	n.	row %	Col %	n.	row %	Col %	n.	row %	Col %
Just sharing (exp level)	39	46	32	4	5	80	34	40	46	8	9	42	85	100	39
Just sharing (info level)	19	57	15	0	0	0	8	24	11	6	19	32	33	100	15
Sugg	13	57	11	1	4	20	9	39	12	0	0	0	23	100	10
Pers. elab	16	89	13	0	0	0	2	11	3	0	0	0	18	100	8
Group elab	35	57	29	0	0	0	21	34	28	5	9	26	61	100	28
тот	122	55	100	5	2	100	74	34	10 0	19	9	100	220	100	100

Table 5.3 – cross tabulation Type of knowledge sharing and construction process x strategies adopted in Step 1

Starting from *Table 5.3*, we want to propose some reflections:

• If in Step 1 the strategy used to present a problem is based on sharing, in more than a half of the cases, the following process stop on Step 2 (sharing or suggesting). In this case, as we already said, participants use the sharing process as a way to normalize their situation and also to collect other experiences or suggestions, that they can use when they share their state, but also in other situation.

^{6.} insuman rapid needs to stay in the fridge and once you open it, 20 days room-temperature, I don't know what one you use

^{7.} yes, it depends on the type of insulin you use... it's better to specify]

- The same type of reflection can be done, if we considered the request of support.
 Who asks to support just needs to be reassured about the fact that others have the same experience or feel the same and that it's possible to copy with the problem/situation
- Instead, if we considered asking about real problem, we found that both strategies stopping at Step 2 and the ones arriving to Step 3 may happen
- Personal elaboration occurs mainly after the asking about the real problem. This is
 pretty evident; indeed one person who has a specific and defined problem is able to
 find a solution starting from the others experiences and suggestions
- Group elaboration is pretty spread, not connected to a specific strategy in Step 1. As previously said, this type of process is activated by the type of problem presented that is perceived as really involving and controversial.

Finally, even if, we already presented the contents that characterize each process, we want to visualize them, by localizing them on the map of content of the knowledge sharing and construction processes we proposed in paragraph 5. 7

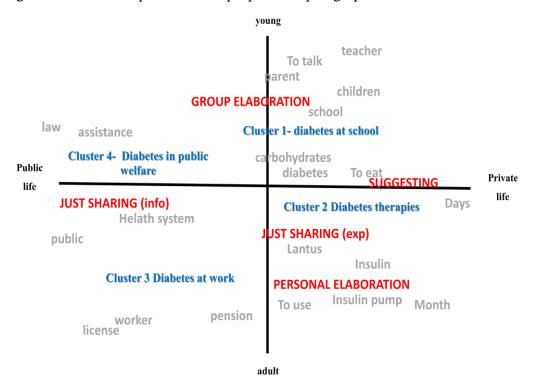


Figure 5.4- Contents map & types of knowledge processes

According to *Figure 5.4* Just sharing (experience level), Suggesting and Personal elaboration refer to the practical management of diabetes and therapies. Just sharing (info) is connected to diabetes in public welfare as it deals with law and regulations about diabetes. Group elaboration touch more controversial issues, in particular connected to the social and public aspects of diabetes and to the diabetes in childhood and adolescence.

5.9 Further reflections

After having presented the different steps and types of knowledge sharing and construction processes, linking their main discursive acts and contents, we want to add to last reflections, that are not central in the understanding of the processes but that may help the reader to have a more complete over view of the analyzed data.

5.9.1 Actors

As already said, the two considered Facebook groups have different participants and actors in the discussions. Group 1 mainly by children caregivers, instead group 2 both by patients and caregivers (adults and children caregivers). Practically, they are quite different in their use of knowledge sharing and construction processes (*Table 5.4*).

	1	2
Just sharing	57(42)	28 (33)
experience		
Personal elaboration	16 (12)	2 (2)
Suggesting	11(8)	12 (14)
Just sharing	13 (10)	20 (24)
Information		
Group elaboration	39 (28)	22 (26)
	136 (100)	84 (100)

Table 5.4- Types of knowledge sharing and construction process x type of online context

Firstly group one presents more knowledge sharing and construction processes, but it presented also more discussions (see *Table 5.2*).

Group 1 (children caregivers) mainly remain at Just sharing (exp level), because its need insights and they need to know that what they are living is normal. Moreover, after their

personal elaboration of suggestions and knowledge given, they give a feedback to the group by thanking or telling the solution of the event/problem (this type of process practilly doesn't happen in group 2). In this group social and emotional issue are really important, so it's important to participants update the others and underline the relevance of the exchanges.

Instead, group 2 the sharing it's not only about personal experience but also of information, as already said linked to laws aspects, research aspects that probably interest more diabetic adults than parents of diabetic children (that don't feel this kind of topic really close to them)

The group elaboration is presented in both the groups even if according to different perspective. In group 1 it's about personal problem connected to management of diabetes, but also the emotional and social aspects of diabetes. Instead, in group 2 it's connected to law and public sphere of the diabetes and the problems connected or about possible new types of revolutionary and controversial therapies.

5.9.2 Multimodal analysis

In this last paragraph, we want to briefly focus on the use of different communication mode

Contrary to our previsions, the use of links, video and pictures is not so spread (*Table 5.5*).

Total messages	7673
Picture	133 (1,7%)
Link	129 (1,7%)
Video	27 (0,4%)

Figure 5.5 Number and percentage of non textual messages

Even if they seem to be marginal communication mode, it's possible to define different functions in the use of them:

 Pictures: illustrative function. Pictures are used to make more real and clear what people are saying. In particular participants to the exchanges share pictures about their daily life connected to diabetes or to the activities they are doing and the places they are

- Links: trustworthiness function. Links are used as warrantor of the credibility of
 information given, in particular when participants are talking about laws, or medical
 information.
- Videos: **emotional and social function**. Video are used to support greetings and social messages, to make their emotional component stronger.

6.5 Conclusive remarks

We will briefly reflect on the results reported in this chapter trying to point out the main important evidences.

First of all, we said that the interactions we considered at the beginning of our analysis are not all supporting knowledge sharing and construction processes. This is a first interesting results. Indeed, part of the studies about knowledge sharing and construction processes, considered all the online discussions or interactions as knowledge sharing and construction activities (e.g. Zenios, 2011). Instead, others (e.g. Hara, & Hew, 2007) underlined that different types of interactions activities happen within an online COP. We agree with this second position. In particular, we think that all the activities aimed to express social and emotional support (such as messages and interactions we called "Greetings" or "Good-Great") are really central in the life of these COP of diabetic patients. Interactions reflect the double need that people have when they join the online COP: find useful knowledge and support (Ancker *et al.*, 2009).

Secondly, we gave an overview of the contents that knowledge sharing and construction give about diabetes. It's evident from these results that the management of the diabetes not only requires attention to therapies, diet, physical activity, but also concerns difficulties connected to the emotional and social impact of this disease on patients and caregivers. We underlined how they considered diabetes as affected many and various aspects of people life (both patients and caregivers) and the necessity for them to have a place where be free to talk and think about diabetes and all the topics concerning; this sustains what we said just above about the necessity of both construction of knowledge and social and emotional support for the patients. Sometimes literature on the topic tend

to differentiate online contexts for the one or for the other purpose. In our opinion diabetic and caregivers need both of them.

After these preliminary considerations, we moved to out-and-out analysis of knowledge sharing and construction process development in term of main phases and possible types of processes.

Firslty, we underlined the problem solving perspective as grounding for knowledge sharing and construction processes. Indeed, in literature different perspectives coexist: some authors found the collaborative learning or the COP (and so the processes of knowledge sharing and construction) on the problem solving logic (Fahey, Vasconcelos, & Ellis, 2007), instead others totally didn't consider the question. This dichotomy is evident if we consider the two models about temporal development we presented in paragraph 5.2 of this chapter, as Gunawardena *et al.* (2001), totally don't consider the problem. This because in learning studies, usually participants to online interactions already hve a specific task to solve (e.g.: An, Shin, & Lim, 2009) and so they move directly to the sharing phase. Our study clearly state that in the case of online knowledge sharing and construction between diabetic patients and their caregivers a problem, and the necessity and will to solve it, is the ground for the development of knowledge sharing and construction processes.

Then, we defined the three main steps of the knowledge sharing and construction processes: Step 1 "Presenting the problem and activating the process", Step 2 "Expliciting and sharing possible solutions", Step 3 "Elaborating and concluding". Practically each step can be expressed by different discoursive strategies. In step 1 people use two main strategies: they ask direct questions (about a specific problem or looking for support); or they share their personal state or information they consider relevant. In step 2 people can share knowledge, experiences and information relevant to solve the problem proposed in step1 or they can propose some suggestions directly "shaped" for that particular problem. Finally in Step 3 the elaboration on the knowledge reached in Step 2 can be: personal, in this case the person who posed the problem in Step 1 concludes the process by stating what he/she has done/will do. Or the elaboration can happen in the group: in this case there is a process of negotiation and possibly conclusion making in the online context.

The steps we detected are partially different from the steps in models proposed by the literature (Gunawardena *et al.*, 1998; Garrison *et al.*, 2001) and used to built the analysis grid:

- 1. As already underlined the knowledge sharing and construction processes born by the identification of a problem. This step is not so clear in the literature models, because, as we previously said, they referred to online interactions happening after a clear task has been asked to the participants in the interactions. So they already have a problem, just the step of identification and presentation of the problem hadn't been considered in the analysis. Morever, in our study the participants themselves expose a problem, that is connected to their real life an not an abstract task. This further confirms that the online contexts analyzed can be considered as COP, that are used by the member in order to solve problems (Wenger, 1998). In this step the sharing of experiences, information and opinions is just a discursive strategies used in order to introduce a problem.
- 2. In our model the sharing of knowledge is not the first step of the process (as in the models proposed by the literature), but it begins after the statement of a problem. It begins the process to the solution of the problem. It is similar to sharing step in literature models (even if it isn't the starting point of the process).
- 3. Then we propose a last step about the elaboration and conclusion making. This step can comprehend step 3-4-5 of Gunawardena *et al.* (1998) and 3-4 of Garrison *et al.* (2001). Indeed this step can comprehend elaboration (if it happen in the group) and it comprehend conclusion (as statement of the solution of the problem, or in case the impossibility to solve the problem).

The definition of the different steps of the processes allowed to differentiate different type of possible knowledge sharing and construction processes. Not all of them arrive at step 3, but they stop after the sharing of knowledge. We summarize the different processes and their features in *Table 5.6*.

	Just sharing	Just sharing	Suggesting	Personal	Group elaboration
	(experience level)	(info level)		elaboration	
Steps	1,2	1,2	1,2	1,2,3	1,2,3
reached					
Discursive	sharing of	quick and	few people	first step:	knowledge
strategies	personal	short	diagnosis of	similar to	sharing +
	experience	exchanges	the problem	sharing	discussion and
	few dialogue	use of links	by direct	experience	elaboration of
	lot of participants		asking	second step:	different
			providing	feedback to	positions
			suggestion	the group	argument and
			focused on	about personal	counter argument
			that specific	elaboration by	possible flame
			problem	thanking or by	not always it lasts
				telling what	with a shared
				happen	knowledge
Contents	treatments	laws	practical	treatments	social issue about
	eating	books	problems	eating	diabetes
		medical	1		
		information			
actors	caregivers	patients	patients	caregivers	patients &
					caregivers

Table 5.6- Summary of the different knowledge sharing and construction processes main features

Actually, we are saying that in the online peer interactions about diabetes, oriented by a problem solving logic (so in a context that can be framed as social constructionist learning- see chapter 4, paragraph 4.2), different types of knowledge processes occur.

This is really important if connected to literature on the topic.

In chapter 3 we proposed many different labels for the knowledge processes. They are various, only considering the field of learning processes (sharing, construction, building, but also absorption). They partially refer to different processes, but usually their definitions overlap (e.g. knowledge sharing is defined as the simple transmission from some authors – van Aalst, 2009 - others instead consider it as knowledge construction – van den Hoof *et al.*, 2003). Moreover the different labels are used as synonymous without consider they have different meanings.

Thanks to: 1. the explorative aim of the study; 2. joint to the context of study: natural (not ah hoc built) online contexts presenting a variety in terms of contents and aspects of the management of diabetes, this study was able to underline the possibility that these different processes coexist. It's important to differentiate them and consider the specific feautures of each one of them.

According to our analysis and considering the labels presented in literature is possible to gather three main type of processes:

- Knowledge sharing, according to the following definition "Knowledge sharing refers to the transmission of knowledge between people" (van Aalst, 2009, p. 260). It is a process that allow people to gain new knowledge, namely new ways to cope with diabetes, by the experiences of others people. Some authors consider it less than knowledge construction (Skinner, 2007). In our opinion, at least for the diabetic patients and caregivers, it seem really useful as: it can construct a repository of knowledge in the online context; moreover in the case of patients and caregivers it allows to normalize experiences and feelings and so it's a way to socially support participants in the interactions.
- Knowledge absorption as it "refers to using the knowledge acquired" (Echeverri, & Abels, 2008, p. 149). Between the processes, we detected personal elaboration. It can be assimilated to knowledge absorption as a person starting from the knowledge acquired in the online contexts is able to apply it into the problem he/she needs to solve. This process, according to our results, practically starts from knowledge sharing (instead usually in literature it start from knowledge acquisition, see table xxx). So, because the knowledge as been acquired by a context socially and emotionally framed, the person who absorbed the knowledge wants to give a feedback about the importance and the helpful of the knowledge shared by others
- Knowledge construction, as "individuals work together on a shared problem, participate in discussion, and arrive at agreed solutions" (Zenios, 2011, p. 259). This is the only process in which people construct (or try to) construct solutions. In our case, as this process happen, the topic of the discussion has to be really engaging and controversial.

Summarizing, thank to this study we were able to define different types of knowledge processes that co-exist in the online interactions between diabetic patients and caregivers and their features.

Conclusion

This work started from the assumption, provided by the literature, that the online peer exchanges are a relevant tool for the patients (and their caregivers) empowerment, as they offer useful information and social and emotional support for the daily management of illness (in particular chronic illness).

Actually, it's possible to state that people can transfer, share and construct knowledge³⁴ (based on the culture, the opinions and the experiences of the members in the exchange) about the care management by online exchanges.

Even if the importance of this phenomenon, we detected two main gaps in the study of online peer exchanges about health:

1. Literature talks about exchanges that happen in the online environment; but it's not possible to consider the online as one single context (especially after the advent of the Web 2.0) as it presents many different options in terms of both technical (e.g.

_

³⁴ For a taxonomy of the different knowledge processes see table 3.1

different Web 2.0 applications) and social features (e.g. memberships and types of participants, types of aims). Do difference contexts allow different types of knowledge processes? How the online contexts can favor or hinder knowledge sharing and construction processes?

2. The health literature mainly focuses on the outcomes (knowledge and contents produced) of the knowledge sharing and construction processes. It's unclear how these processes function. What is the temporal development? What the main steps? What the discursive strategies use in the development of these processes?

The research presented in this dissertation, focusing on the specific case of diabetes, has tried to answer to these questions by the development of three main studies (phases) focused on the different aspects of the questions.

In the next few pages we will outline the main results of each study and show their theoretical and practical implications.

Study one

It was aimed to map the Web 2.0 contexts in which peer exchanges about diabetes happen, in order to define:

- The types of knowledge processes activated by the different online contexts
- Possible online contexts for the development of knowledge sharing and construction processes.

Key evidences

We were able to define 4 types of online contexts supporting different knowledge processes and characterized by different Web 2.0 applications, contents and actors.

In particular two psycho-social dimensions seem to rule the variation of online contexts supporting peer exchanges: "legitimation of the knowledge produced in the exchanges", namely who guarantee for the content produced and "Relational aim of the exchanges", namely the orientation toward the spread of information or toward the sharing and participating in a discussion within a particular group of reference. On the base of these

two axes, we defined four types of contexts that presented different orientation toward knowledge processes:

- Popularizing, aimed to spread knowledge (mainly scientific) produced by someone else. Main Web application used: blogs; main actors: experts and general public; content: scientific information.
- Exhibiting aimed to diffuse knowledge toward the activities of single individuals or specific group; Main Web application used: personal blogs, Facebook pages; main actors: mix of different actors; content: general information about diabetes and people/associations linked to it
- Educating, aimed to allow discussion with experts of relevant topic and transfer of knowledge; Main Web application used: forums, chats; main actors: experts (e.g. health practitioner) and patients; content: diabetes therapies
- *Interacting*, aimed to the participation into discussions among peers and in the sharing and construction of knowledge useful for pragmatic aims. Main Web application used: forums, Facebook groups; main actors: patients and their caregivers; content: practical management of diabetes and support

This last type if context seem the one more able to support knowledge sharing and construction processes between patients and their caregivers.

Theoretical implications

Our results showed that different Web 2.0 contexts support different knowledge processes. This is important because studies on knowledge processes usually refer to online as a single context without consider that it has different options right inside.

Instead, we can say that the different types of knowledge processes, theorized by different field of literature (e.g.: knowledge transfer and translation in health communication&promotion; knowledge diffusion Internet&communication studies; and knowledge sharing and construction in studies about learning in the educational and organizational field), happen in online contexts characterized by different social and technical features, different contents, different actors.

Figure A summarize on which online context each field of literature focus on.

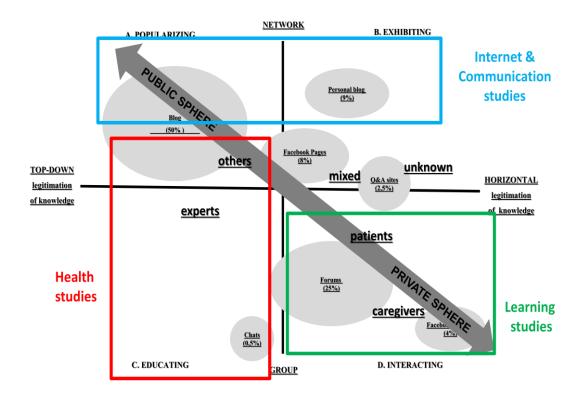


Figure A- Graphical localization of knowledge processes theoretical approaches

According to this statement, it will be important in the study of the online knowledge processes, always define the features of the online context we are considering,

Moreover, the differences between online contexts are based on psycho-social dimension not only on technical dimension. This statement is important, as a big field of study about online contexts, also in health, just focuses on technical dimensions.

Practical implications

In our opinion, this study presents some practical implications for the use of the different online context by the health expert system:

1. Popularizing for prevention: throughout the use of blogs, it is possible to make general public aware of the diabetes world. In particular blogs are able to transfer knowledge to a indefinable number of people. That make evident the relevance these type of Web 2.0 tools may have in the prevention world.

- Exhibiting for fund and resources raising: here it's possible to make the general
 public aware of the practical efforts of associations and organizations towards
 diabetes. These types of contents may help these organization in fund and
 resources raising.
- 3. *Educating for clinical relations*: throughout synchronous and asynchronous tools, the web 2.0 is able to practically sustain relation between practitioners and patients. This area is not really used for now in Italy, but it has a big practical potential into facilitate the clinical relation.
- 4. *Interacting for patient empowerment*: this area spontaneously born by the need of patients and their caregivers to find help and support. The world of association and organization haven't so far totally understand the potential of this area in order to orientate good care&cure practices. Moreover it's evident that patients and caregivers needs are not the same and they need adequate tool to find the adequate type of support for them.

The opportunity to orientate online contexts on the basis of the aims we want to reach is fundamental for health promotion success.

Study 2

We focused on those online contexts that by Study one we identified as more able to support knowledge sharing and construction processes. Anyway, they showed big differences in their ability to support interactions and knowledge sharing and construction processes.

Therefore Study 2 was aimed to define the online context social and situational features that may foster or hinder interactions and knowledge sharing and construction processes.

Key evidences

Starting from theories on learning, we considered COP (community of practice) as theoretical framework guiding our analysis.

We reached three main results:

- The COP paradigm can be applied to the online contexts in which interactions
 between diabetic patients and caregivers occur, as basing on it, we were able to
 differentiate online contexts according to their ability to support interactions and
 knowledge sharing and construction processes.
- We were able to define the main ingredients that make an online context able to support interactions and knowledge sharing and construction processes. We summarize them in Table A

Ingredients	Description
Aim	- clearly stated
	- concerning both informational and support aspects
Boundaries	- close online context, perceived as a safe group
	- connected to the other online and offline aspects of the participants life
Affiliation	- linkages with patients associations are guarantee for online context value
	- avoid connections to pharmaceutical organizations
Immediacy in	- in order to supply limits of the offline relationship
the answer	- provided by: updated technology + core group of people who strongly participate in
	the exchanges
Moderation	3 types of concurrent moderation:
	-The "puller": group/people stably participating to the interactions, by posting topics
	and answering questions
	- The "facilitator" helping to solve practical and technical questions
	- The "controller" checking the group participants and exchanges
Cultural	- diabetes 1 people more involved (also for the type of illness)
diversity	- patients: more focused on practical solutions to diabetes management problems
	- caregivers: more focused on support
	- you can reach only patients who wants to be reach
Time	- need time to construct online contexts perceived as safe places
framework	- need to be updated about technological development
Size	- High number of participants can foster the number of interactions
Contents	- deal with diabetes 360 degrees

Table A – Ingredinets for "In a top shape" online contexts

3. Based on these dimensions we were able to classify the analyzed online context toward their degree of "fitness" in support interactions: In top shape (supporting a lot of starting posts and interactions and the possibility to share and construct knowledge); In a discrete manner (supporting less posts, but again an high percentage of interactions allowing the possibility to share and construct knowledge); Need to keep more fit (supporting many starting posts, but low level of interactions); Totally out of shape & Died (not able to support interactions between participants).

Theoretical implications

In our opinion this work has three main theoretical implications:

- a) We can state that COP can be applied as a model to understand online contexts that support interactions between diabetic patients and their caregivers. We reviewed literature about learning processes in order to detect a model helpful into define the features of a context supporting knowledge sharing and construction processes. The most fitting seemed to be COP model, anyway the possible application of this framework to online patients interactions was just theorized and never been applied. By our study we were able to state that online contexts which support knowledge sharing and construction processes between diabetic patients and their caregivers can be assimilated to COP, as they present the COP main features.
- b) Literature concerning with online COP just proposed possible typologies of online COP, but any evidences about dimensions that could indicate the wellbeing (or fitness) of these COP and their ability into support interactions and knowledge sharing and construction processes haven't been proposed. We were able to identify the main dimensions according to their ability to support interactions, that may distinguish "in shape" online contexts from "out of shape" ones. This is just a first exploration of the topic but it could be the basis for further reflection aimed to construct a tool/grid for online contexts evaluation.
- c) Moreover the study is an attempt to put together the different features, both technical and social, that shape online contexts. Indeed literature focus on specific aspects and there is a need to find tool able to consider the different aspects of the online contexts in order to classify and differentiate them.

Practical implications

We think this study can be helpful for:

a) Developing online contexts "tailored" on people: we think that the dimensions we underlined can guide different health professionals that more and more face with the necessity to find Web 2.0 solutions for help patients. We considered the natural

occurring online interactions, but our reflections will be useful to anyone interested into support or create or address (in the meaning of "use for a specific purpose") online contexts "tailored" on people needs.

b) Developing tools for the online contexts of peer exchanges evaluations. As said before these indications could be a base to built tools/grid able to evaluate the ability of online contexts to support interactions.

Study 3

It was aimed to understand how knowledge sharing and construction works in online interactions between diabetic patients and their caregivers, by focusing on its temporal development and main phases, the interactive (discursive and conversational) dynamics, and the contents.

Key evidences

Firstly, we were able to define the main steps of knowledge sharing and construction processes in online interactions between diabetic patients:

- Step 1 "Presenting the problem and activating the process": we understand that
 knowledge sharing and construction processes are aimed by a problem-solving logic.
 So the first step of the process is the statement of the problem by: asking direct
 question (about a specific problem or looking for support); or sharing personal state
 or information about diabetes.
- 2. Step 2 "Expliciting and sharing possible solutions": this the phase aimed to collect knowledge (experiences in formation) that can be the base for solve problems. Practically, people can share their knowledge, experiences and information or they can propose some suggestions directly "shaped" for that particular problem.
- 3. Step 3 "Elaborating and concluding": this step comprehend the elaboration of the shared knowledge .This elaboration can be personal: in this case the person who posed the problem concludes the process by stating what he/she has done/will do. Or the elaboration can happen in the group: in this case, people activate a process of negotiation and possibly conclusion making in the online context.

Moreover, we understood that different types of knowledge sharing and construction are possible. Not all of them arrive to step 3.

We were able to detect five types of processes: Just sharing (experience level), Just sharing (information level), Suggesting, Personal elaboration, Group Elaboration.

In our opinion they are guided by three main logic (retrievable in literature):

- Knowledge sharing, underpinning Just sharing (experience level), Just sharing (information level), Suggesting. Thanks to this type of process, knowledge gained by one in his/her personal life has made available to the others In the case of diabetic patients and caregivers, it seem really useful as: it is repository of helpful and practical knowledge towards management of diabetes; it allows to normalize experiences and feelings, being a way to socially support others.
- Knowledge absorption (Personal elaboration). Starting from the knowledge acquired
 in the online contexts, a person is able to apply it into the problem he/she needs to
 solve, recognizing the relevance of the knowledge the others shared.
- Knowledge construction (Group elaboration) as people in the online context try to negotiate opinions and experiences in order to develop solutions to a problem

Theoretical implications

The implication of this study is twofold:

- We were able to define how online knowledge sharing and construction processes between diabetic patients and their caregivers and supported by Facebook groups work. Literature models were always been applied into educational context and supported mainly by forums. We were able to define the phases the discursive strategies used and the contents dealt
- 2. Learning studies (that were our starting points) proposed many different labels for the knowledge sharing and construction processes, often overlapping and often used as synonymous. By our study we stated that different processes can happen. They are different and they can't be used as synonymous but refer to different way to share and construct knowledge.

Practical implications

Practical implication of this Study 3 are connected to the possibility to be capable of construct interactions and interactions places that answer to the needs of patients and caregivers and to support helpful knowledge sharing and construction processes. In particular, to know how they construct knowledge and what they need is the first step to plan patient empowerment oriented activities, tools and services.

Final concluding remarks

Summarizing we can say that this work helps to systematize concepts connected to the knowledge sharing and construction about diabetes happening in online contexts, concerning three main topics:

- 1. Online knowledge process, by defining the different online contexts (and their social and technical features) that support the different types of knowledge processes
- 2. Online contexts, by defining the dimensions that make them able to supporting interactions
- 3. Online knowledge sharing and construction processes, by defining main types, their steps, their discursive features and their contents.

These results are preliminary and need verification: they can be considered a first step in the study of the online knowledge sharing and construction between patients. In our opinion the findings outlined here need to be confirmed by further analyses with particular focus on:

- The extent to which the typologies of online contexts and knowledge processes might be considered stable:
 - When dealing with different chronic conditions
 - In different socio-cultural contexts (we considered only the Italian context)
- The development of more structured indicators for:
 - Dimensions of online contexts supporting interactions and knowledge sharing and construction processes.

Appendix A- Analysis grid for study 1

Site descriptive grid

- Descriptive data
 - ✓ Numbers of posts/articles/discussion about diabetes
 - ✓ How long people talking about diabetes?
- Web relevance
 - ✓ Number of registered people
 - ✓ Number of visitors
- means/medium
 - ✓ Blog
 - ✓ Journal Blog
 - ✓ Forum
 - ✓ Social network
 - ✓ Chat
 - ✓ Q&A sites
- Exchange activities
 - ✓ Post
 - ✓ Mailing the post
 - ✓ Share the post on other social networks/sites/blogs
 - ✓ Like
 - ✓ Like on FB
- Main theme of the site
 - ✓ general
 - ✓ health
 - √ diabetes
 - ✓ other
- When does diabetes arrives?
 - ✓ Site's name
 - ✓ In the forum/thread
 - ✓ In a specific section
 - ✓ In the single post/discussion
- Site affiliation
 - ✓ Association
 - ✓ hospital
 - ✓ Patient/s
 - ✓ Web communication agencies
 - ✓ Blog platform
 - ✓ Experts
 - ✓ Anyone
- Affiliation indexes
 - ✓ Logo
 - ✓ Copyright
 - ✓ Contacts/References
 - ✓ Admin name or nickname
- Site trust
 - ✓ Contacts/links

- ✓ Authors profile/description/bionote
- ✓ Mission
- User profile (Do you have to enroll to participate into the discussion?)
 - ✓ Need to enroll
 - ✓ Participate as host
 - ✓ No registration needed (but you can register if you want)
 - ✓ No possibility to enroll
 - ✓ Blog platform enrollment
- *Profile type* (what kind of information?)
 - ✓ Nickname
 - ✓ Picture
 - ✓ Other information (socio-demographic)
 - ✓ Info about participation
 - √ Facebook profile
- Required information to post
 - ✓ No information required
 - ✓ Name/nickname
 - ✓ E-mail
 - ✓ Facebook/ other SN contacts
 - ✓ Web site
 - ✓ Enrollment information

Exchanges descriptive grid

- Main descriptors
 - ✓ Participation data
 - ✓ Visiting data
 - Exchange lasting (1 day; less than 1 week; 1-2 weeks; less than 1 month; less than 3 months)
 - ✓ Number of posts
- Actors
 - ✓ Patients
 - ✓ Care givers
 - ✓ Practitioners
 - ✓ Pharmacists
 - ✓ Psychologists
 - ✓ Admin
 - ✓ Other interested people (not patient)
 - ✓ Not possible to define
- Exchange way
 - ✓ words
 - ✓ pictures
 - ✓ links
 - ✓ video
- Users' Needs
 - ✓ Information
 - ✓ Support
 - ✓ Sharing
- Trust toward other participants
 - ✓ Chance to verify other's identity

- → Shared friends
- → Presence of profles
- → Information from the site
- → "meeting in the real world"
- → Precedent exchanges
- ✓ To have some features in common
 - → Illness
 - → socio-demo
 - \rightarrow therapy
 - \rightarrow other interests

Appendix B- Study 1: words specificities for actors clusters

CAREGIVERS	S		
Overused specif	ficities		
EMMA	CHI2	SUB	TOT
mum	724,36	193	287
children	698,83	224	376
good morning	677,82	137	168
our	286,04	209	555
beautiful	282,64	140	304
to see	219,04	195	567
hello	165,7	179	565
school	164,89	69	136
to live	160,91	89	205
to understand	158,07	141	410
to hope	134,23	95	248
insulin pump	125,06	105	297
hug	120,12	46	86
friend	120,04	75	184
to feel	112,11	106	316
PATIENTS			
Overused specif	ficities		1
LEMMA		CLID	ТОТ
	CHI2	SUB 93	TOT 245
to write	221,4		
hello	193,24	153	565
breakfast	152,53	55	132
lunch	135,52	56	146
to eat	69,52	128	661
dinner	66,97	44	148
examination	48,64	40	150
bolus	40,54	30	107
glycemic curve		35	135
driving license	39	30	109
insulin pump	36,77	60	297

to believe	35,55	37	154
question	35,54	40	172
to find	30,6	72	401
glycemic index	28,08	162	1122

cancer	-5,4	3	102
substance	-5,31	2	85
university	-4,88	6	141
urine	-4,06	4	103

EXPERTS

Overused specific	ities		
LEMMA	CHI2	SUB	TOT
professor	461,99	106	185
doctor	223,71	107	298
cancer	209,77	54	102
sport	149,12	61	155
physical activity	116,38	94	343
meal	58,47	88	415
carbohydrate	52,77	77	359
value	37,01	48	214
metformin	33,98	24	82
glycemic index	25,15	162	1122
to eat	24,54	104	661
transplant	22,86	26	110
therapy	22,67	57	317
lantus	21,31	20	78
unit	19,28	30	143
	•		•

Underused specificit	ies		
LEMMA	CHI2	SUB	TOT
health	-12,83	8	250
week	-12,02	11	286
life	-8,57	37	582
scuba diver	-6,35	3	109
test	-5,43	3	100
to see	-4,81	41	567
to understand	-4,63	3	92
head	-4,52	5	120

MIXED

Overused specific			
LEMMA	CHI2	SUB	TOT
help	187,17	108	211
to eat	151,8	225	661
sweet	105,16	100	247
glycemic curve	95,09	64	135
young	91,42	114	314
type	87,58	62	134
kg	69,34	50	109
medical	60,22	77	214
examination			
pregnancy	58,63	78	220
to request	57,43	48	112

Underused specificit			
LEMMA	CHI2	SUB	TOT
patient	-54,22	23	518
study	-45,89	11	355
university	-20,94	3	141
obese	-17,54	5	144
professor	-16,29	10	185
subject	-16,16	9	175
treatment	-15,86	5	135
life	-14,02	62	582
to develop	-11,3	8	138
transplant	-11,26	5	110

diet	53,24	160	581	style	-7,07	7	104
bread	48,01	48	121	choice	-5,66	5	78
to walk	41,93	36	85	system	-5,44	14	150
week	37,32	85	286				1
hello	30,58	141	565				
OTHER							
Overused specifi	icities			Underused specific	Underused specificities		
LEMMA	CHI2	SUB	TOT	LEMMA	CHI2	SUB	TOT
specialist	407,59	22	53	glycemic index	-7,88	2	544
diabetic	87,93	25	231	our	-5,04	1	326
practitioners	75,03	26	274	to find	-4,27	1	289
type	72,79	31	372				
medical	47,17	16	166				1
examination							
drug	43,07	10	80				
certificate	23,97	4	25				
to understand	20,98	19	340				
message	18,2	6	61				
case	11,26	8	127				
to write	8,43	10	201				
patients	7,46	5	77				
complications	6,48	4	59				
internet	5,83	3	40				
	1	 	+			+	

Appendix C - Analysis grid for Study 2

<u>Interactions description</u>:

- The number of starting posts in one month
- The number of discussions activated by a starting posts in one month
- Comparing two periods of time (October 2011 and October 2012)
- 1. Demographics:
 - a. Aim
- Presence of a aim
- Topic of the aim
- b. Age: year in which the online context born/discussions about diabetes began
- c. Online context focus:
 - Sites about diabetes vs specific section
 - Diabetes in general vs. specific aspect of diabetes
- 2. Membership characteristics:
 - a. <u>Size</u>: the number of the people enrolled.
 - b. Geographic dispersion:
 - spread around all the Italy
 - located in a specific area
 - c. Members' selection process: open vs close groups
 - d. Members' enrollment: the type of enrollment required to participate.
 - e. <u>Members' prior community experience</u>: references to previous online context's discussions or activities.
 - f. Membership stability: presence of a stable core group
 - g. <u>Cultural diversity</u>:
 - Patients vs caregivers
 - Type of diabetes
- 3. Context:
 - <u>Affiliation</u>: patients or caregivers vs support of associations, research centers, hospitals or other organizations.
 - b. Boundary crossing:
 - Offline
 - Other online contexts
 - c. Leadership and moderation:
 - Presence of active person/group
 - Presence of founding members
 - Presence of moderator
- 4. Technological environment:
 - a. <u>Degree of reliance on offline</u>: references to offline meetings and exchanges
 - b. Type of Web 2.0 application: forums versus Facebook groups .

Appendix D – Analysis grid for Study 3

- 1. Temporal development
 - a. sharing & triggering event
 - b. negotiating and elaborating
 - c. testing and applying
- 2. Discursive acts of the different knowledge sharing and construction phases:
 - a. Sharing & Triggering event phase:
 - i. Solicitation,
 - ii. Seeking help
 - iii. Seeking feedback
 - iv. Require personal opinion
 - v. Asking a question
 - vi. Share personal experience
 - vii. Sharing information
 - b. negotiating and elaborating phase:
 - i. Asking for clarification
 - ii. Giving clarification
 - iii. Suggesting
 - iv. Agreeing
 - v. Disagreeing
 - vi. Sharing personal experience and opinions
 - vii. Sharing information
 - viii. Help giving
 - ix. Feedback living
 - x. Judging
 - xi. Criticing
 - xii. Revising other's point of view
 - c. testing and applying phase
 - i. Acknowledging learning something new
 - ii. Acknowledging importance of subject being discussed
 - iii. Discussing
 - iv. Statement of application
 - v. Conclusion making
- 3. Discursive acts related to social and emotional support
 - a. Social discursive acts
 - i. Thanking, namely
 - ii. Greetings

- iii. Explicit mention of belonging to the group
- iv. Explicity use our
- v. Direct replying
- vi. Explicit mentioning of another expertise
- b. Emotional discursive acts
 - i. Asking for assurance and support
 - ii. Consoling:
 - iii. Giving support and consolation
 - iv. Encouraging
 - v. Expressing empathy
 - vi. Using humour
- c. We also considered possible communication problems
 - a. Flaming
 - b. Misunderstanding

Appendix E- Number and Percentage of different knowledge and construction processes

	n.	%	n.	%
	messages		discussion	
Just sharing (experience level)	1239	27	85	39
Just sharing (info level)	367	8	33	15
Suggesting	272	6	23	10
Personal elaboration	268	6	18	8
Group elaboration	2503	53	61	28
TOT	4649	100	220	100

Appendix F- Study 3: words specificities for knowledge sharing clusters

JUST SHARING	EXPERIENC	ES					
Overused specific	cities			Underused spec	cificities		
LEMMA	CHI2	SUB	TOT	LEMMA	CHI2	SUB	TOT
glycemic index	44,11	81	165	teacher	-35,79	5	135
expire	40,23	32	48	vaccine	-19,34	3	75
menstrual cycle	39,01	25	34	practitioner	-12,37	18	137
pregnancy	33,67	29	45	to talk	-12,11	48	279
insulin pump	24,88	129	337	protein	-12,09	1	41
to accept	23,66	32	59	to explain	-11,99	10	94
nutella	22,62	18	27	you	-6,98	29	167
glycosilated hemoglobin	22,08	61	139	to exceed	-4,7	1	20
attached	20,88	9	10				
cost	20,88	9	10				
week	20,44	37	75				
medical	18,84	31	61				
examination							
worker	17,44	9	11				
grandpa	17,33	13	19				
to sleep	17,25	33	68				
JUST SHARING		ION					
Overused specific	cities			Underused spec	cificities		
LEMMA	CHI2	SUB	TOT	LEMMA	CHI2	SUB	TOT
pharmacy	142,9	18	40	insulin pump	-14,93	1	337
region	112,11	13	27	to feel	-8,37	3	278
patronage	93,85	7	10	life	-4,23	2	157
ticket	89,3	11	24				
family practitioner	84,71	8	14				
procedure	76,05	6	9				
Http	63,09	14	48				
insurance	58,09	7	15				
thank you	51,06	31	200				
euro	48,62	9	27				

to pay	43,21	8	24				
ASL	38,95	10	38				
Italian	32,56	5	13				
to ask	32,56	5	13				
service	32,56	5	13				
SUGGESTING							
Overused specific	cities	Underused specificities					
LEMMA	CHI2	SUB	TOT	LEMMA	CHI2	SUB	TOT
capillary	167,74	8	11				
cortisone	114,33	6	9				
stick	77,76	5	9				
supply	46,58	5	14				
to suppose	42,64	4	10				
glycosilated	35,37	17	139				
hemoglobin							
to eliminate	34,28	4	12				
test	34,28	4	12				
venous	34,28	4	12				
together	32,24	7	34				
husband	31,66	10	63				
to distress	31,07	4	13				
drug	31,07	4	13				
to happen	28,85	12	90				
to regulate	28,33	4	14				
PERSONAL ELA	ABORATION						
Overused specific				Underused spe	ecificities		
LEMMA	CHI2	SUB	TOT	LEMMA	CHI2	SUB	TOT
meal	53,27	22	88	our	-9,55	1	174
metformin	50,54	7	13	teacher	-6,97	1	135
values	50,19	18	66	school	-4,49	5	195
thank you	47,75	36	200				
glucagon	37,81	10	30				
to correct	37,35	12	41				
continuous	35,6	7	17				
to bounce off	35,53	6	13				
diabetician	33,22	20	99				

insuman	25,36	8	27						
God	20,94	6	19						
nausea	20,87	5	14						
to answer	20,47	14	74						
sugar	19,93	14	75						
hug	19,89	11	52						
GROUP ELAB	ORATION								
Overused specificities					Underused specificities				
LEMMA	CHI2	SUB	TOT	LEN	MMA	CHI2	SUB	TOT	
teacher	60,58	123	135	to e	xpire	-48,91	4	48	
children	48,21	182	225	glycemic		-37,78	57	165	
				inde	ex				
parent	20,76	75	92	stic	k	-34,21	5	40	
protein	20,15	38	41	wee	k	-16,96	26	75	
son	19,14	165	228	regi	on	-11,5	7	27	
cure	17,52	76	96	valu	ies	-11,11	25	66	
sensibility	17,36	34	37	prog	gram	-10,86	1	11	
class	16,4	41	47	before		-8,41	127	258	
people	16,19	38	43	OK		-8,2	21	54	
vaccine	16	43	50	urin	e	-7,21	4	16	
home	15,52	101	135	suga	ar	-6,14	33	75	
word	14,28	50	61	test		-5,41	3	12	
discourse	13,2	25	27	to c	alm	-5,41	3	12	
school	12,9	138	195	unit		-4,18	25	56	
to die	12,56	40	48						
	i i		1			1			

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